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ABSTRACT

The focus of the six seminar papers is on the rehabilitation needs of persons with long-term mental illness, followed by excerpts of reviews and comments, as well as summary recommendations. "Rehabilitation Programs in the 1980s: Laying the Groundwork for the 1990s" (William Anthony) notes that deinstitutionalization is a historical fact and discusses psychiatric rehabilitation, family psycho-education, and case management as intervention approaches for the future. Paul Carling, in "Housing and Support for People with Psychiatric Disabilities: Directions for the 1990s," advocates promoting normal integrated housing and consumer choices, reorganizing services, and restructuring finances to promote supported housing. In "Housing: A Crucial Dimension," Jerry Dincin discusses capital funding, operational funding, zoning, and the stigma of mental illness. Joan Barker delineates advantages of a successful interagency agreement in "Coordination of Efforts Between Vocational Rehabilitation and Mental Health Systems." Esso Leete, in "The Role of the Consumer Movement and Persons with Mental Illness," offers the perspective of a person living with schizophrenia. "The Role of the Family in the Rehabilitation Process" (Agnes Hatfield) describes the purposes and ideology of the National Alliance for the Mentally Ill (NAMI), a coalition of self-help groups for families. There are three brief concluding papers which address the consumer self-help movement, service needs of mentally ill deaf persons, and strategies for change in policy, programs, training, research, and legislation. (JW)

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Rehabilitation of Persons with Long-Term Mental Illness in the 1990s

A Report of the 12th Mary E. Switzer Memorial Seminar

Leonard G. Perlman and Carl E. Hansen, Editors

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Switzer Memorial Seminars

As a living tribute to the memory of Mary E. Switzer, each year a special topic of vital interest to the rehabilitation of persons with disabilities is explored in depth. One of the outcomes of each seminar is a Switzer Monograph which clarifies the thinking in a given area of rehabilitation and sets goals and objectives for positive action. Those individuals invited to participate in the seminar are designated as Switzer Scholars.

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The *Switzer Monograph* reflects the writings, discussions and recommendations of the 20 Switzer Scholars at the 12th Annual Switzer Seminar held June 15-17, 1988, at Gallaudet University in Washington, D.C. Opinions expressed in the *Switzer Monograph* are those of the writers and not the policy of the National Rehabilitation Association or any other organization.

The National Rehabilitation Association is a non-profit organization dedicated to improving the quality of life for people with disabilities.

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Switzer Monograph

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Introduction

It is an appropriate memorial tribute to the late Mary E. Switzer to have the 12th Mary E. Switzer Seminar study the issues and needs of persons with long-term mental illness. The importance of this topic to the field of vocational rehabilitation is reinforced in that this is the second time that the subject of mental illness has been featured in a Switzer Memorial Seminar. The first one took place in 1979 and explored the needs and developed recommendations for the decade of the 1980s. Much has happened in the rehabilitation of persons with mental illness since the Fourth Switzer Memorial Seminar, but much more needs to be accomplished as we prepare for the decade of the 1990s.

The seminar was held in Washington, D.C. from June 15-17, 1988, and was hosted by Gallaudet University. Welcomes were provided by Dr. Irving King Jordan, President of Gallaudet University; Dr. Frank R. Zieziula, Chairman, Department of Counseling; Dr. Marita Danek, Director, Rehabilitation Counseling Deafness, both from Gallaudet University; Dr. Robert E. Brabham, Executive Director, National Rehabilitation Association (NRA); and Dr. James R. Burress, former President of NRA and Commissioner of Region 8 of the Rehabilitation Services Administration. Dr. Burress provided a brief overview to the Switzer Scholars of Mary E. Switzer with whom he had worked for several years.

The Switzer Planning Committee, in outlining goals and directions of the 12th Switzer Memorial Seminar, provided a number of subtopics critical to the enhancement of the rehabilitation potential of persons with a long-term mental illness. Examples of the papers written for the seminar include the following titles:

- Rehabilitation programs in the 1980s: Laying the groundwork for the 1990s
- Housing and support for people with psychiatric disabilities: Directions for the 1990s
- Housing: a crucial dimension
- Coordination of efforts between vocational rehabilitation and mental health systems
- The role of the consumer movement and persons with mental illness
- The role of the family in the rehabilitation process

The above areas of concern provided the foundation for the three-day seminar. Reviews and comments were made by the Switzer Scholars and excerpts of these comments are included to provide the various perspectives of the Switzer Scholars who represented a broad cross-section of disciplines, consumers and relatives of persons with mental illnesses. In addition, the major recommendations and implications for action are noted as they were developed during the course of the seminar.

Considerable effort has gone into the development of this text and the findings and recommendations. It is the hope of the Switzer Scholars and the Switzer Memorial Committee that this information will stimulate communications between the various professional disciplines, consumers, relatives of consumers, policy makers, employers and anyone interested in the habilitation and rehabilitation of persons with long-term mental illness. Much remains to be done, yet when we look back a decade or two and see how far we have come, there is continued optimism that the next decade (the 1990s) will bring even greater progress for this large and important target population. We welcome the challenge.

Tribute to Mary E. Switzer

The following words were stated by Dr. James R. Burress shortly after Miss Switzer's death in 1971 at a memorial service held at the then Health, Education and Welfare (HEW) auditorium in Washington, D.C. This quote is used since it captures the essence of Mary Switzer, the person and her unique qualities as seen through the eyes of a long-time colleague and friend.

I am especially privileged to have this opportunity to pay public tribute to Mary E. Switzer. I was especially privileged to have known and enjoyed a very personal relationship with Mary Switzer. At this time, many warm words of praise will be said about the indomitable spirit, her humanitarianism, her compassion, her loyalty and dedication to fair play and equality of opportunity for all people--yes, Mary Switzer was a woman of rare intellect, energy, ability, and human compassion. Although she held many important posts in public life and received the accolades of many, she truly reached her zenith when she couched in each of us her love and compassion for the handicapped among us in such a unique way that we would never forget, and in the process never forget her and what she stood for--a fine and sensitive woman, a courageous leader, and a timely great humanitarian.

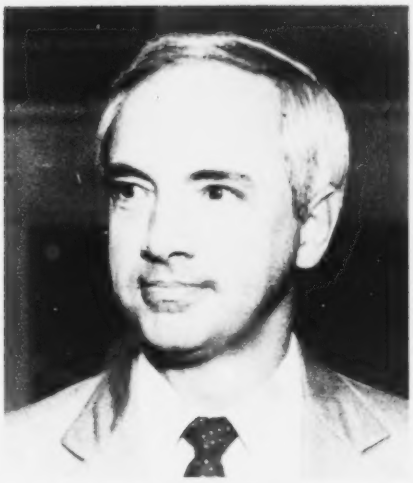
I first met Mary Switzer early in 1951, shortly after she became Director of the Office of Vocational Rehabilitation. I was a rehabilitation counselor with the D.C. Vocational Rehabilitation Service. I shall never forget that day. She sat at my desk and talked about the work of the rehabilitation counselor . . . the problems and trials, the successes and failures and the joys and sorrows . . . She was searching for information. She was deeply concerned, more so than anyone I have ever known.

We talked many times since that day in 1951 . . . . She always left me with greater hope. She was my counselor, a friend of my family, in whom we enjoyed a warm and personal relationship.

Mary Switzer's confidence, support, and encouragement will ever remain the inspiration and guiding light for all I do.

All of us in the National Rehabilitation Association, and in the broad sector of rehabilitation programs, nationally and internationally, and all handicapped and disadvantaged people are better because she passed our way.

May God grant her eternal peace and her light and spirit be ever upon us. **--Dr. James R. Burress**



Robert E. Brabham, Ph.D.
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Switzer Seminar Coordinator

Foreward

It is with great pleasure that we honor the memory of Mary E. Switzer with this publication concerned with the rehabilitation of persons with mental illness. I am reminded of Miss Switzer's inspired leadership as the U.S. Commissioner of Vocational Rehabilitation when rehabilitation grew in depth as well as breadth. It was during her tenure that the doors to services to those with a mental illness were opened. This was in the late 1950s. Since that time rehabilitation has had a prime interest in this target population.

Times, of course, do change and with them, come new needs and innovations. The issues of deinstitutionalization, the rise of community mental health centers, consumerism, new and more effective medications, and the rise of homelessness have all added to the mix, causing us to rethink our policies and approaches to working with persons with mental illness.

The Switzer Scholars with their varied experiences and expertise from the fields of mental health and vocational rehabilitation bring us a fresh new distillation of ideas and directions in order to better serve those with a long-term mental illness as we set our sights on the decade of the 1990s.

The 20 Switzer Scholars have provided in this *Switzer Monograph* a broad-based set of ideas and recommendations for action in areas such as employment, housing, training, policy and service delivery and the reduction of stigma. As the Switzer Scholars have pointed out, the challenge before us is a great one, but it is within our reach. The basic ingredients included a coordinated and cooperative venture by all interested parties who wish positive change.

On behalf of the National Rehabilitation Association, I wish to thank Dr. Hansen and Dr. Perlman and the members of the Switzer Planning Committee for their year-long efforts on the seminar. We also deeply appreciate the support of our eight sponsors.

Readers interested in this subject may also be interested in NRA's drug manual presented at the 1988 Switzer Seminar. Joan Barker, past president of the National Rehabilitation Association and a 1988 Switzer Scholar, initiated this important work to give consumers as well as rehabilitation counselors the information they must have to assist their clients who are receiving prescription medications. Its title is *Medications Frequently Used to Treat Persons with Mental Illness*; its author, Helen Lisanby Danser, is a registered pharmacist from Kentucky.

I sincerely hope that this *Switzer Monograph*, dedicated to one who cared deeply in the worth of the person, will stimulate increased interest and action on behalf of people with mental illness.

--Bob Brabham

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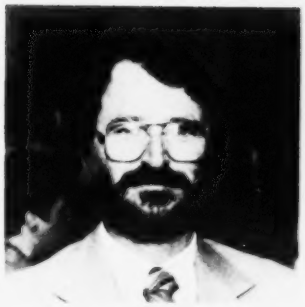

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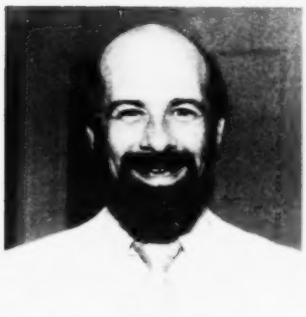

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Thanks are expressed to all who played a part in the planning and implementation of this memorial tribute to the late Mary E. Switzer.

Special appreciation is expressed to the following persons: The Switzer Memorial Committee members, Bertram J. Black, Karel Disponett, Susan Suter, and Richard Switzer for their support and guidance; the Planning Committee for the seminar who helped to shape and design this seminar (their names are listed in this report); Irving King Jordan, President of Gallaudet University for hosting the seminar with style and grace; Neal Brown, Chief, Community Support and Advocacy Branch of the National Institute of Mental Health (NIMH) and David Miller, Project Officer of that Branch for their encouragement and assistance during the planning as well as the implementation phases of the seminar; Jay Rochlin, Executive Director of the President's Committee on Employment of People with Disabilities for his constant support of the seminars over the years and to Larry Jewkes, President of NRA; Robert E. Brabham, Executive Director of NRA and his fine staff; and to NRA Publications Manager Donna Weiss for the production of this publication.

Appreciation is also expressed to the Switzer Scholars for giving so freely of their time and talents to making the 12th Seminar a memorable one.

Mary E. Switzer
1900-1971

Few people realize that Mary E. Switzer had a satisfying and fully successful career in federal government employment that spanned several decades prior to her formal entry into the field of rehabilitation. She was fifty years old when she became director of the Office of Vocational Rehabilitation in 1950, and she brought to the position a superior intellect and ability. Her many talents and experiences in economics, the legislative process, government administration, health, welfare and public education were only a few of the composite assets brought with her. She entered the movement at a crucial point in its evolution. It was a time in which difficult decisions had to be made between maintaining the status quo or moving to a larger and unknown future but with increased opportunity to serve tens of thousands of people with disabilities yet in need.

Following a life pattern in support of increased services to people with a more responsive and humanitarian government to changing human needs, she readily committed herself to the less certain but more hopefully expanded future for rehabilitation. The rest is history. The breadth and humanity of Mary Switzer are stamped forever in the passage of Public Law 565 with its research and demonstration features, its concern for rehabilitation education, its mandate to construct necessary rehabilitation facilities, its totally new characteristic of international efforts and cooperation regarding rehabilitation, and perhaps, above all, in its expanded funding base for more personnel and programs for those in need of rehabilitation services. In the years that followed, she went on to even greater legislative and governmental leadership heights in behalf of both disabled and disadvantaged people.

Despite the demands on the national and federal scene, her presence was almost ubiquitous in behalf of program development and extended services to needy people. On a regional, state or local level, be it public or voluntary services, if it were in the interest of rehabilitating those in need, somehow, she would "arrange to be there."

The WHO'S WHO has chronicled her many national and international awards. Also recorded are her presidencies of many organizations including the National Rehabilitation Association, whose members and their efforts she held in high esteem. But she did not reach the heights of her ability when she was made the first Administrator of the Social Rehabilitation Services, not when she retired from the position, nor when she became internationally involved in the World Rehabilitation Fund. Instead, she found her greatness when she touched each of us bringing our full humanitarian efforts and qualities to the fore in behalf of disabled and disadvantaged people. While readily recognized as a truly great administrator in the classical sense of the word, her true capacity and ability can only be appreciated when we realize that these accomplishments sprang from an inner expression of sensitivity, emotional refinement and dedication to serve all less fortunate people. Her egalitarian qualities were not contrived but spontaneous, stemming from love and respect for all living things.

All of in the National Rehabilitation Association and in rehabilitation and all people with disabilities have had better, more meaningful, and more productive lives because her presence and her being were sufficiently large to embrace and accept us as we are and help us better understand where we should be.

What more can be said than we had the joy and privilege of knowing her?

This memorial tribute is quoted from E.B. Whitten, *Journal of Rehabilitation*, November/December, 1971.

Rehabilitation Programs in the 1980s: Laying the Groundwork for the 1990s

William A. Anthony

The 1980s can be seen as a decade of transitions--a transition between the former era of deinstitutionalization and the future era of rehabilitation. The decade of the 1980s sounded the death knell for whatever was left of the deinstitutionalization era. This same decade can be seen as the harbinger of rehabilitation. As we move to the decade of the 1990s we need to talk less about deinstitutionalization and more about rehabilitation.

If ever there were an issue no longer worthy of debate it would be--Was deinstitutionalization a success or failure?

Deinstitutionalization is a historical fact. A return to the era that preceded it, that is, institutionalization of large numbers of persons with psychiatric disabilities, is an economic impossibility. Society will simply not pay for it. The question is--Where do we go from here? The direction to that question is provided by psychiatric (psychosocial) rehabilitation.

William A. Anthony, Ph.D., is the Director of the Center for Psychiatric Rehabilitation at Boston University.

Deinstitutionalization focused on how buildings function; rehabilitation focuses on how people function. Deinstitutionalization focused on closing buildings; rehabilitation focuses on opening lives. Deinstitutionalization focused on getting rid of patient restraints; rehabilitation focuses on getting hold of person supports.

In contrast to the deinstitutionalization initiative, with its focus on emptying buildings, rehabilitation, with its focus on people outcomes, is a field in which one can become excited and enthusiastic. Interestingly, a deinstitutionalization goal of fewer people living in institutions for fewer days can also be realized by rehabilitation. In achieving this same outcome from a rehabilitation perspective, however, one can be guided by rehabilitation values and principles.

In the final analysis, deinstitutionalization was an easy task when compared to rehabilitation. Deinstitutionalization opened the **doors of the hospital** and gave people a **prescription for their medicine** when they left. Rehabilitation tries to open the **doors of the community** and help people develop a **prescription for their lives.** The deinstitutionalization era is dead--it is yesterday's focus. The rehabilitation era is upon us. It guides our current activities and gives us a vision of the future as we move toward the 1990s.

Considerable progress in the field of psychiatric rehabilitation has occurred since the convening of the Fourth Mary E. Switzer Memorial Seminar entitled, "The Rehabilitation of the Mentally Ill in the 1980s" (Perlman, 1980). In the 1980s, programs that served persons with psychiatric disabilities have moved from a deinstitutionalization mentality toward a rehabilitation mentality. Rehabilitation is an approach which can guide our practice not only in vocational programs and psychological rehabilitation centers (Beard, Propst, & Malamud, 1982), but also in community mental health centers (Fishbein, in press), inpatient settings (Marlowe, Spector, & Bedell, 1983), residential environments (Blanch, Carling, & Ridgway, 1988), educational environments (Unger, Danley, Kohn, & Hutchinson, 1987), and in the family environment (Spaniol & Zipple, in press).

In the early 1980s rehabilitation programs and their practitioners were known by the principles that guided their practice (Anthony, Cohen, & Cohen, 1984). At the Fourth Switzer Seminar, Grantham (1980) characterized rehabilitation as

holistic, valuing adaption to the environment, focusing on the severely disabled, de-emphasizing psychotherapy and personality reconstruction, and emphasizing the need for a range of services, program accountability and case management. However, Grantham (1980) cautioned that the principles and ideology of rehabilitation were not well articulated and that this conceptual confusion was a barrier to an agreed upon set of rehabilitation program activities.

The decade of the '80s has seen the principles and values of rehabilitation become better articulated so that the conceptual understanding of rehabilitation has markedly improved.

Concurrently a consensus has begun to emerge on those program activities which reflect these rehabilitation values. Furthermore, these concepts and program activities are grounded in a developing base of empiricism. The present paper focuses on those conceptual, programmatic and empirical developments which have characterized the 1980s and which prepare the path to the 1990s.

Conceptual Developments

The conceptual advances occurring at the time of the Fourth Switzer Conference (Perlman, 1980) are now well articulated and cemented into the values and philosophy of psychiatric rehabilitation. What constitutes rehabilitation for persons with psychiatric disabilities has been "officially" defined.

> Psychosocial rehabilitation refers to a spectrum of programs for persons with long-term, severe psychiatric disabilities. The goal is to improve the quality of life for these individuals by assisting them to assume responsibility over their lives and to function as actively and independently in society as possible. The programs are designed to both strengthen the individual's skills and to develop the environmental supports necessary to sustain the individual in the community.
>
> Major services, which may be offered on a continuum, should be coordinated with those offered by other agencies providing psychiatric, as well as the broad array of human services. The specific services include opportunities to meet social/recreational needs, vocational training and job placement, rehabilitative residential services, training in the skills of daily and community living, and case management services. In addition, some psychological rehabilitation programs include client assessment and goal planning activities, educational programs, and family support activities.
>
> The services, which the individual may need to use on a short-term basis or indefinitely to achieve or maintain community adjustment, are provided in the context of a supportive, normalizing environment in the community. They are offered in a manner that emphasizes the "personhood" rather than the "patienthood" of the individual, that maximizes the individual's responsibility, control and feelings of self-worth, and that encourages ownership in the rehabilitation process. (Stockdill, 1985, p. 3)

Psychiatric Rehabilitation and the Community Support System

The preceding definition of psychiatric rehabilitation recognizes the broad range of rehabilitation services, the major interventions of skill and support development, and the fundamental values of psychiatric (psychosocial) rehabilitation. These fundamental values of rehabilitation, articulated many times over (Anthony, 1982; Beard, Propst, & Malamud, 1982; Dincin, 1981; Grob, 1983; Lamb, 1982) are consistent with the values of the National Institute of Mental Health's Community Support System initiative (Stroul, 1988). Indeed the development of the Community Support System (CSS) has spurred the development of the field of psychiatric rehabilitation (Mosher, 1986).

As initially described by Turner and TenHoor (1978) the 10 components of the CSS initiative include 7 components that are often provided by comprehensive psychosocial rehabilitation centers such as Fountain House (Mosher, 1986). Because the values underlying the CSS are essentially rehabilitation in origin and perspective, the decade of the 1980s has seen CSS and the field of psychiatric rehabilitation develop in a complementary fashion. The description of a CSS, with its focus on the essential functions provided by a comprehensive service system, defines the context in which the psychiatric rehabilitation approach should be provided. The settings and technology of psychiatric rehabilitation, as exhibited in its program structures and intervention strategies, have served to operationalize the CSS philosophy and functions within a comprehensive, research based, rehabilitation treatment approach. In summary, the CSS initiative and the psychiatric rehabilitation field are compatible with respect to their philosophy, service delivery context, primary intervention strategies and target population.

The Population Served by Psychiatric Rehabilitation

The focus of psychiatric rehabilitation is on persons who have experienced a severe psychiatric disability. This group can be contrasted to individuals who are simply dissatisfied, unhappy, or "socially disadvantaged." Rather, persons with severe psychiatric disability are persons with a diagnosed mental illness which has limited their capacity to perform certain functions (e.g., interacting with family and friends, interviewing for a job) and their ability to perform in certain roles (e.g., worker, student).

There are several definitions of severe psychiatric disability which present a convergent description of this population. Three of these definitions are the definitions currently used by CSS, the Rehabilitation Service Administration's (RSA) definition of severe disability, and Goldman's (Goldman et al., 1981) definition of the "chronically mentally ill." The National Institute of Mental Health has developed an operational definition of adult clients served by the CSS initiative (NIMH Grant Announcement for CSP, 1980). This operational definition describes two major criteria which are consistent with most definitions of persons who are severely psychiatrically disabled.

1. Severe Disability Resulting from Mental Illness

CSS clients typically meet at least **one** of the following criteria:

- Has undergone psychiatric treatment more intensive than outpatient care more than once in a lifetime (e.g., emergency services, alternative home care, partial hospitalization or inpatient hospitalization).
- Has experienced a single episode of continuous, structured supportive residential care other than hospitalization for a duration of at least two years.

2. Impaired Role Functioning

CSS clients typically meet at least two of the following criteria on a continuing or intermittent basis for at least two years.

- Is unemployed, is employed in a sheltered setting, or has markedly limited skills and a poor work history.
- Requires public financial assistance for out-of-hospital maintenance and may be unable to procure such assistance without help.
- Shows severe inability to establish or maintain a personal social support system.
- Requires help in basic living skills.
- Exhibits inappropriate social behavior which results in demand for intervention by the mental health and/or judicial system (pages iii and iv of NIMH Grant Announcement for CSS, 1980).

Another working definition of this population has been provided by Goldman, Gattozzi, and Taube (1981). They describe the severely psychiatrically disabled along three dimensions: diagnosis, disability, and duration. The approximation of 1.7 to 2.4 million severely psychiatrically disabled individuals is often based on their analysis. Goldman et al. (1981) have identified the "chronically mentally ill" as having a severe mental disorder (typically psychotic) with moderate to severe disability (functional incapacity) of prolonged duration (most often a period of supervised residential care).

Another definition of severity is used by RSA as defined by the 1973 Rehabilitation Act. The act defines a severe handicap as a "disability which requires multiple services over an extended period of time." One of the specific impairments cited as causing a severe disability is mental illness. A disability is defined as either a physical or mental condition which limits a person's activities or functioning. The severely disabled are the first priority of service as mandated by the Rehabilitation Act of 1973.

Each of the preceding definitions (CSS, Goldman, RSA) shares common elements, that is, a diagnosis of mental illness, a prolonged duration, and functional or role incapacity. The predominant characteristics of the persons who are the focus of this Switzer Seminar reflect these three dimensions. These dimensions transcend traditional diagnostic categories, and describe a population that is characterized by significant vocational and social deficits and neurotic-like responses to sources of stress (Summers, 1981). Persons with long-term mental illness are not continuously and flagrantly symptomatic; flagrant symptomatology is episodic and does not characterize the person's day-to-day activities.

Complementary Nature of Rehabilitation and Psychiatric Treatment

As rehabilitation becomes better articulated it becomes more possible to make useful comparisons between treatment and rehabilitation. When most persons think of treatment for the long-term mentally ill what often comes to mind is medication and psychotherapy. The intervention of psychiatric rehabilitation, with its emphasis on skill and support development designed to help persons function in their chosen environment, is obviously very different from treatment. As the field of psychiatric rehabilitation moves into the next decade, we need to make sure that we conceptualize the treatment model and rehabilitation model as complementary models rather than as competing models.

In the past, proponents of psychiatric rehabilitation have been perceived by some to be the anti-treatment, or anti-medicine and/or anti-therapy. This is puzzling, as good treatment and good rehabilitation should go hand in hand. Yet treatment professionals have been heard to say that the rehabilitation approach forces one to choose between a rehabilitation perspective and a treatment perspective.

It now appears that this perceived antagonism may be due to the fact that rehabilitation professionals are anti-"bad"-treatment and not anti-treatment per se. What is meant by "bad" treatment is treatment that does not involve the client in the treatment--for example, when medications are used over the long term without any understanding by or input of the client. "Bad" treatment occurs when treatment is deemed all-important or is all that is offered to the client. Treatment is "bad" that does not acknowledge or support the need for rehabilitation for persons who are severely psychiatrically disabled. "Bad" treatment does not recognize its own limitations, that is, that medication and insight alone can't teach skills or provide supports.

Good treatment is the opposite of the above, and is highly complementary to the psychiatric rehabilitation approach. Psychiatric rehabilitation complements treatment that involves the clients, helps them to understand their treatment, and recognizes and promotes the usefulness of rehabilitation. Treatment of this type, combined with psychiatric rehabilitation is a potent and complementary combination.

Family and Consumer Self Help and Advocacy

A fundamental value of psychiatric rehabilitation, reinforced by the CSS initiative, is the critical importance of consumer and family involvement in rehabilitation. Both consumers and families have suggested a need for rehabilitation services. A survey of consumers and family members reported consensus around the need for placing more treatment emphasis on rehabilitation approaches (Lecklitner & Greenberg, 1983).

With respect to the interest of family member self-help/advocacy groups, Spaniol has surveyed a national sample of

members of the National Alliance for the Mentally Ill (Spaniol & Zipple, in press). The National Alliance for the Mentally Ill (NAMI) has become the major voice of the relatives of persons who are severely psychiatrically disabled. Families in this study and others (Castenada & Sommer, 1986) have reported that the greatest need for improved services were social and vocational rehabilitation services.

With respect to ex-patient or consumer self-help advocacy, the actual differences between consumer self-help and psychiatric rehabilitation approaches do not exist with respect to many of the basic values and goals; however, differences do exist with respect to who is in charge. Proponents of self-help believe it is critical that the leadership and the helpers are consumers. They too look for persons with expertise, based on their ability to be a source of assistance and help, independent of their academic credentials. As elaborated further by Chamberlin (in press):

> There are a number of similarities between the psychiatric rehabilitation approach and that of ex-patient self-help groups (given, of course, the overriding difference that the psychiatric rehabilitation approach is both professional and formal). Unlike many mental health interventions, psychiatric rehabilitation depends on the cooperation and the active involvement of the client. The stress that psychiatric rehabilitation professionals put on doing things only **with** clients (and not to or for them) is one that strikes a responsive chord in people who, all too often, have been subjected to paternalistic, coercive, or compulsory interventions. Similarly, the stress on the individualization of the psychiatric rehabilitation approach compares favorably with impersonal or depersonalizing practices that are all too familiar to most clients. For these reasons, many individuals may choose to combine being members of ex-patient self-help groups with being clients of psychiatric rehabilitation professionals, and such a combination should work well."

Programmatic Developments

The most critical program developments occurring since the Fourth Switzer Conference have been the specification and replication of various types of rehabilitation programs. Programmatic structures, processes and outcomes have been described in sufficient detail so as to facilitate adaptation and replication. Training curricula to train practitioners to work in community support and rehabilitation programs have been evaluated. Rehabilitation programs and rehabilitation practitioners are no longer defined by what they **don't do** (e.g., the eschewal of intensive psychotherapy and the singular use of drug treatment) but by what they **do**.

With respect to program structure and process, a number of program models have been successfully replicated. Best known are the "clubhouse" model (Beard et al., 1982) and the "PACT" model (Test & Stein, 1978). The PACT model (Program of Assertive Community Treatment) has been adapted to urban (Witheridge, Dincin, & Appleby, 1982) and foreign locations (Hoult, 1986). Sites that have adapted the PACT model are now serving as resources for the replications of the adaptations (Bond & Boyer, in press). The clubhouse model as developed by Fountain House is also into its second generation of replications. Training at Fountain House has resulted in an increase in the number of clubhouses to over 240.

The essential elements of a psychiatric rehabilitation program, independent of the particular type of setting in which it is practiced, have been described by Anthony, Cohen, and Farkas (1982). These elements include such dimensions as: client involvement in setting one's overall rehabilitation goal, functional and resource assessments, skill teaching and resource development interventions. A program assessment methodology capable of assessing these various program ingredients has been developed and tested. Results indicate that mental health agencies that are attempting to move toward a rehabilitation approach are only beginning to implement into practice the concepts they value, for example, client involvement, skill and resource development interventions (Farkas, Cohen, & Nemec, 1988). However, because the structure and process of a psychiatric rehabilitation program is now capable of being observed and monitored it is now possible to facilitate program change toward a psychiatric rehabilitation program structure and process. Kelner (1984) and Fishbein (in press) have presented data describing a state-wide movement toward a psychiatric rehabilitation program in one state's partial care settings.

In addition to the advances in defining and changing program structures, the 1980s have witnessed the specification of some of those skills basic to the practice of psychiatric rehabilitation (Anthony, Cohen, Farkas, & Cohen, in press). Practitioner training programs have been developed and researched (Rogers, Cohen, Danley, Hutchinson & Anthony, 1986). Psychiatric rehabilitation practitioners can be taught such skills as the ability to conduct functional assessments, to teach skills to clients, and to set overall rehabilitation goals. Furthermore, a training-of-trainers strategy has been created in order to teach supervisors how to teach these skills to other staff (Rogers et al., 1986).

Case Management

The concept of case management, promoted by the articulation of the CSS initiative in the 1970s, has taken root in the 1980s. The need for case management is evidenced by a number of factors. These include the numbers of persons who are homeless, mentally ill, and/or not connected to services and benefits (Billig & Levinson, 1987; Ridgway, 1986); data indicating that typical discharge planning greatly underestimates the needs for services other than medical/therapeutic aftercare services (Wasylenki et al., 1986); the generally recognized system fragmentation and lack of coordination of existing services (Rapp & Chamberlain, 1985); and the fact that many clients do not follow through on referrals or drop out of services.

A number of articles relevant to case management were published in the 1980s. Most of the writings on case management are descriptive in nature and have focused on such issues as: the characteristics of case managers (e.g., Intagliata & Baker, 1983; Caragonne, 1981; Goldstrom & Manderscheid, 1983); description of the focus of case

management activities (e.g., Baker & Weiss, 1984; Berzon & Lowenstein, 1984; Caragonne, 1983; Intagliata, 1982; Kurtz, Bagarozzi, & Pollane, 1984; Levine & Fleming, 1984; Marlowe, Marlowe, & Willets, 1983); ideal caseload size and its impact on the process of case management (e.g., Intagliata & Baker, 1983; Schwartz, Goldman, & Churgin, 1982); or the relative merits of individual vs. team case management (Turner & TenHoor, 1978). It appears that variations of case management programs will continue to be developed in the 1990s. Case management is more than a response to a dysfunctional system. No matter how integrated or coordinated the system, persons who are disabled often need a caring person(s) to guide them through their rehabilitation (Anthony, Cohen, Farkas, & Cohen, in press).

In summary, the development, specification, and observable demonstrations of a number of different types of rehabilitation interventions are prerequisites for the conduct of empirical research on program impact. There is little payoff in researching an intervention that cannot be specified to the level that permits replication. Future research and program utilization are hampered if a vague, ambiguous intervention is analyzed.

Empirical Developments

The field of rehabilitation is still in its infancy with respect to empirical studies. The earlier quasi-experimental studies are a foundation for the better-controlled studies which have begun to emerge in the 1980s. Particular areas of intervention have been stressed and will probably continue to be researched into the next decade. These areas will include psychiatric rehabilitation, family psycho-education, and case management.

Psychiatric Rehabilitation

Anthony and Blanch (in press) and Dion and Anthony (1987) recently reviewed the empirical data with respect to psychiatric (psychosocial rehabilitation. Dion and Anthony (1987) reviewed 35 experimental and quasi-experimental studies that attempted to change the skills and/or environmental supports of persons with psychiatric disabilities. Studies were included in the review regardless of whether or not the researcher specifically called the intervention psychiatric rehabilitation. Dion and Anthony (1987) provide a tabular overview of all 35 studies described in terms of treatment setting, environmental focus, types of outcome measured, type of intervention, research design, and findings. Within the limitations of measurement and research design, their review suggests that psychiatric rehabilitation interventions positively affect rehabilitation outcome on measures such as recidivism; time spent in the community; employment and productivity; skill development; and client satisfaction (Dion & Anthony, 1987).

As reported by Anthony and Blanch (in press), other reviews have analyzed a specific intervention area relevant to rehabilitation. Unger (in press) & Unger et al. (1987) have reviewed descriptive and conceptual data on a relatively new setting for rehabilitation--post-secondary educational environments. The social skills training (SST) literature has been reviewed periodically (Brady, 1984; Hersen & Bellack, 1976; Morrison & Bellack, 1984; Wallace et al., 1980). Morrison & Bellack (1984) note that SST has not made a major difference in patient's lives. It appears that SST holds the most promise as a specific technology in which it is but one component of a more comprehensive rehabilitation intervention (Anthony & Liberman, 1986; Liberman et al., 1986; Wallace & Liberman, 1985).

Bond and Boyer (in press) have reviewed research on vocational programming for persons who are psychiatrically disabled. Of the controlled studies which they reviewed, four studies reported positive results, two studies found marginally significant results, and thirteen studies found no difference between experimental and control groups. In contrast, when investigators examined whether experimental subjects were more successful in sheltered or transitional placements, seven of eight studies favored the experimental. In an earlier review of vocational programming by Anthony, Howell, and Danley (1984), they identified several other positive studies of vocational programming (e.g., Kline & Hoisington, 1981).

The 1980s have seen vocational programming, consistent with the philosophy and principles of rehabilitation in general, moving toward the concept of on-going job support (Anthony & Blanch, 1987). Supported employment is the term used to describe a vocational intervention characterized by permanent competitive employment, in integrated settings, with on-and-off job site support for as long and as intensively as one needs it. The concept of supported employment originated in the field of mental retardation and has been extended, albeit with programmatic differences, to persons with disabilities (Anthony & Blanch, 1987). The only published research to date compared successful and non-successful supported employment participants. The successfully employed persons were more apt to become disabled prior to age 19; consistent with previous vocational research, no difference between the two groups was found in severity of symptomatology, diagnosis, and functioning in other life contexts (Trotter, Minkoff, Harrison, & Hoops, in press).

Family Psychoeducational Interventions

The 1980s have witnessed a growing interest in assisting families and their ill family members to cope with the stresses of living with a psychiatric disability.

Data have clearly shown the psychological, social, physical, and economic impact on the family of living with a long-term mentally ill family member (Fadden, Bebbington, & Kuipers, 1987; Lefley, 1987; Spaniol & Zipple, in press). Over one-third of long-term mentally ill adults live with their families (Fadden et al., 1987; Lefley, 1987). The question of the 1980s was--what will help family members cope with this situation and promote the integration of the ill family member into the natural community support system?

Research on approaches to families, loosely categorized as "psycho-educational," have demonstrated their effectiveness in reducing the relapse rate of ill family members, and/or in providing support and information to the family itself (Anderson, Hogarty, & Reiss, 1980; Falloon et al., 1982; Goldman and Quinn, 1988; Goldstein & Kopeikin, 1981; Hogarty et al., 1986; Jacob, Frank, Kupfer, Cornes, & Carpenter, 1987; Leff, Kuipers, Berkowitz, Eberbein-Vries, & Sturgeon, 1982; Smith & Birchwood, 1987; Speigel & Wissler, 1987). A review by

Zipple and Spaniol (1987) suggested that these types of approaches, no matter what their conceptual base meet all or some of the most critical needs of families.

Zipple and Spaniol (1987 categorize these existing approaches into four kinds: 1) educational approaches; 2) skill development approaches; 3) supportive approaches; and 4) comprehensive approaches. They concluded that each type of approach seems to significantly reduce relapse. A multi-site, NIMH funded research project is currently investigating the impact of a psycho-educational approach in interaction with medication, using a broad range of outcome criteria (NIMH, 1986).

Case Management

While the process of case management has been written about extensively, outcome studies are just beginning to appear in the 1980s (Anthony, Cohen, Farkas, & Cohen, in press).

A recent review of case management outcome studies (Anthony & Blanch, in press) reported that the data are sparse and contradictory, with some studies suggesting a positive impact on at least some measures of client outcome (Curry, 1981: Goering, Wasylenki, Farkas, Lancee, & Ballantyne, 1988; Modrcin, Rapp, & Poertner, in press; Muller, 1981; Rapp & Chamberlain, 1985: Rapp & Wintersteen, 1988) and others suggesting little or no impact on client outcomes (Cutler, Tatum, & Shore, 1987; Franklin, Solovitz, Mason, Clemons, & Miller, 1987). For example, two of the most recent, best-controlled studies reported different case management outcomes (Franklin et al., 1987; Goering et al., 1988). Franklin et al. (1987) evaluated a generalist approach to case management compared to the "usual" aftercare services of a community mental health center (i.e., treatment, referrals, medication). In a pretest/post-test design, over 400 clients were randomly assigned to experimental and control groups. The findings were that for the 138 experimental subjects and 126 control subjects interviewed after 12 months of participation, those in the case management program received more services, cost more to maintain, and had higher recidivism rates without any increase in quality-of-life measures. In contrast to the lack of positive results reported by Franklin et al. (1987), Goering et al. (1988) found that case management had an impact on measures of instrumental role functioning, independent housing status, and social isolation. Differences favoring the case-managed clients over a matched historical group increased over the two-year follow-up period. Both Franklin et al. (1987) and Goering et al. (1988) suspect that the usual follow-up period in case management studies (six months to one year) may not be long enough to measure the impact of case management. They also speculate that, while the linking foundation of case management is crucial, the number and types of community resources that exist to which case managers could link a client may well affect the extent to which a case manager can impact on client outcome measures. Clearly, the reviewed interest in case management will generate significantly more outcome research into the next decade.

Rehabilitation in the 1990s: After the 12th Switzer Conference

Between the fourth and 12th Switzer Conference on Psychiatric Rehabilitation, events have occurred from which there will be no turning back and which will forever influence the field. Consumers and family members have entered the arena and demanded to play a role in treatment decisions and policy deliberations. The psychiatric rehabilitation field has moved inexorably toward acknowledging this role. Future conceptual, programmatic, and empirical developments will be increasingly effected by the actions of those advocacy groups.

As suggested by Anthony (1986), the key to designing systems that work is to listen to the consumer of the service. The primary source of the policymaker's learning should be the service recipients and their families, not the professionals and their theories. The "lock them up" mentality and the "turn them loose" mentalities were similar in that the services clients want were provided in neither place. When you ask clients what they want, their answers indicate that they want what most folks want--a decent place to live, a job, friendships, support in time of crisis. These are the goals by which future rehabilitation achievements should be measured.

The rehabilitation of persons with psychiatric disabilities will continue to improve wherever local, state and national systems commit themselves to rehabilitation outcomes for their clients. Policies which drive systems must be explicit about the overriding mission or goal and the accompanying philosophy and values which anchor that goal.

A client-centered system goal capable of guiding mental health/rehabilitation systems is: "to maximize the opportunity for persons who are disabled to function as independently as possible in the living and working environments of their choice, with the level of support and services they need to do it."

As psychiatric rehabilitation moves into the 1990s, our philosophy and values will continue to change from:

1. Trying to create least-restrictive environments to trying to create the **person's most preferred environment.**
2. Constructing a continuum of care to arranging a **repertoire of resources.**
3. Designing types of buildings to designing types of **supports and services.**
4. Professionals placing clients to **clients choosing places.**
5. Providing "make work" in make-work environments to **developing real work in real-work environments.**
6. Figuring out where people should be put to figuring out **what supports and services people want.**
7. Believing that the direction in which we proceed comes from our books and their theories to believing that the **direction comes from the people we serve and their families.**
8. A predominant focus on cost containment to **renewed focus on life enhancement.**
9. A deinstitutionalized-era mentality with its stress on

increasing the opportunity for freedom in a person's life to a rehabilitation orientation with its concern for **increasing the opportunity for life in that person's freedom** (Anthony, 1986, p. 56).

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Switzer Scholars (l to r) Christy Disher, Esso Leete and William A. Anthony, Ph.D., discuss recommendations at the 1988 Mary E. Switzer Memorial Seminar.

Excerpts of Reviews & Comments

The following are excerpts of reviews, comments and recommendations made by the 1988 Switzer Scholars. These are presented to further stimulate thinking, discussion and action as they relate to the content of "Rehabilitation Programs in the 1980s: Laying the Groundwork for the 1990s" by William A. Anthony, Ph.D.

Anthony's paper gives a nice overview of the major rehabilitation developments that are pertinent to serving the seriously mentally ill.

I. I do believe, with Anthony, that emphasis upon rehabilitation will be the hallmark of the 1990s. However, I expect that the movement towards incorporating rehabilitation principles into mental health services will be slower than he estimates is likely.

II. It is not correct to label the 1980s as "the former era of deinstitutionalization." Deinstitutionalization is a catchword, a "buzzword" as it were. Deinstitutionalization, as Bachrach pointed out some time ago, was over years ago. What we have been living through is an era in which the role of the mental hospitals has been transposed to a strictly medical one, and the focus of care and treatment of the severely mentally ill has been forced out into communities ill or unequipped to meet the needs.

III. It is logical to see rehabilitation as the integrating movement that the mental health field keeps talking about needing, but the major controllers of mental health services are not yet seeing rehabilitation as anything more than an adjunct, albeit necessary, set of services. They have not yet accepted what I consider to be two basic principles of rehabilitation, no matter what the disability or handicap:

That rehabilitation should begin as close to the onset of disability as is possible; and

That rehabilitation should take place in an environment as close to that of normal living as is possible.

IV. The Community Support System (CSS), though highly significant, and on its way to becoming more central to mental health services for the seriously mentally ill, is still treated by the mental health establishment as peripheral to the core of community mental health services, and is likely to be so treated for some more years at least.

V. What is called for at this stage of development is much more training of mental health practitioners in the principles and methods of rehabilitation, much more education of rehabilitation practitioners about mental illness, and concerted education of both in the potential capacities and capabilities of persons with severe mental illness. In this education, consumers have an important role to play. We must first address the residual stigma of mental illness among the very professionals and practitioners who purport to treat and rehabilitate before we can expect much change among the general public.

-Bertram J. Black

Dr. Anthony's paper is an excellent summary of the most significant change which mental health systems have undertaken in the last decade: the shift from an institutional mentality to an approach which focuses on the community support needs and the rehabilitation potential of people with psychiatric disabilities. As such, this paper not only traces the significant changes in thinking, in services development, and so forth, that have already taken place, but articulates well the challenge which systems, programs, practitioners and advocates will all have to address if they are to move beyond the rhetoric of rehabilitation toward the reality of full community participation and integration.

The paper is also a sensitive and pragmatic one, in that it addresses some of the thornier "debates" which have emerged in the last decade, such as "Is rehabilitation the same as, or even compatible with, mental health treatment?" "Is rehabilitation just another service, or is it an entirely different way of thinking about people, programs and systems? Dr. Anthony also describes well a number of emerging rehabilitation program models, along with the implications of a rehabilitation approach for case management. And the final section of the paper on "Rehabilitation in the 1990s" is an excellent description of the values by which we should measure all of our planned changes in programs and systems in the coming years. In fact, it would be a highly useful "barometer" for planners and advocates, regardless of the level of the system in which they operate.

The following comments focus on two additional areas which seem centrally relevant to rehabilitation in the 1990s, the inclusion of which would strengthen the paper. The first involves practitioner attitudes, an area which Dr. Anthony touched on briefly. In fact, in visiting "rehabilitation" programs one shortcoming which is all too common involves agencies developing new services without discarding the same tired assumptions about people with psychiatric disabilities and about their potential. This is also true in terms of their attitudes about families. The reality is that many programs have not come to grips with the kind of radical attitude change that is often necessary in moving from a traditional day treatment or day hospital approach to a rehabilitation approach. In a more subtle way these unchanged assumptions are sometimes found in some "psychosocial rehabilitation" programs which continue to resist meaningful and powerful roles for consumers and their families, and which continue to serve consumers in ways that segregate them from regular community activities, and which do not give them the skills and support to become more integrated and successfully functioning community members. Regardless of superficial changes in our "technology," if our basic assumptions about people with major mental illnesses do not change, neither will their opportunities.

Finally, Dr. Anthony's earlier writings have stressed the importance of viewing rehabilitation as a comprehensive approach in which the individual, the service system and society as a

whole become legitimate targets of reform. While this paper is an excellent summary of how practitioners and programs are changing and need to change, it would also have been highly useful in a paper oriented to the future, to look at the analogous changes which need to take place in systems (both mental health and other related systems), and, as importantly, in society as a whole, if positive rehabilitation outcomes are to become more commonplace. The harsh reality that most consumers live below the poverty level, often in substandard housing suggests that individual or even program-wide rehabilitation interventions, by themselves, may do little to change people's overall status or satisfaction. Similarly, without addressing the pervasive discrimination against people with mental illness labels, the life opportunities of these individuals will remain largely curtailed. So what is needed is an articulation of the social change agenda which a rehabilitation approach both suggests, and requires, if we are to improve peoples' lives on a broader scale basis.

-Paul J. Carling

Dr. Anthony's paper focused on 1. the conceptual, 2. programmatic, and 3. empirical developments which characterized the 1980s in preparation for the 1990s. Rehabilitation for persons with psychiatric disabilities has been defined according to the spectrum of programs to improve the quality of life of the long-term severely psychiatric client in the least restrictive environment.

The Psychiatric Rehabilitation and Community Support Systems are compatible in philosophy, service delivery, primary intervention strategies and target population. There are several definitions of severe psychiatric disability, the common elements being the diagnosis, duration, functional and role incapacity. The psychiatric rehabilitation approach emphasizes the skill and support development to help the client to function in his or her chosen environment. The roles of the family and client/consumer and self-help groups are outlined. Various types of rehabilitation programs have been specified and reproduced with staffing and training patterns evaluated according to services provided. The essential element in the psychiatric rehabilitation program is client involvement, skill teaching and resource development. Case management is essential to avoid homelessness, and fragmentation, lack of coordination of existing services. Dr. Anthony focused on designing systems that work based on consumers of the services.

Dr. Anthony has clearly charted the movement from the deinstitutionalization era to the rehabilitation era. I am in agreement that quasi-experimental studies are only a foundation and that published research can provide guidelines and information not only to the professionals but the consumer and the family. The advocacy will continue to guide the mental health/rehabilitation systems. Funding has always been an issue in terms of providing adequate and appropriate services--the area must not be overlooked.

-Jacquelyn Dickerson

This paper does an excellent job of clarifying the important components of a psychiatric rehabilitation program. It recognizes the multifaceted needs of individuals with chronic mental illnesses and addresses how we can meet these needs. The focus, throughout the paper, is on improving the quality of life for people by creating programs that respect their will and provide them with opportunities for growth and development.

In terms of policy/program development the paper points to the need for psychiatric rehabilitation programs to be comprehensive systems which provide or have access to a wide array of services. Programs must be structured to meet the psychiatric and rehabilitative needs of individuals. The concept that the treatment model and rehabilitation model are complementary, rather than competing models in an important framework for the development of effective programs. Programs that provide treatment alone ignore individuals' basic human needs to lead productive lives. The lack of perceivable rehabilitative opportunities can decrease an individual's desire to comply with treatment. On the other hand, ignoring the treatment needs of people can prevent them from taking advantage of rehabilitative opportunities. Programs should also be designed to meet other basic needs such as housing, socialization, medical/dental care, and other case management services. Services which include family members are also important.

In looking at the rehabilitative needs of individuals we need to ask what methods of training are most successful with what populations. Many of the training programs for people with disabilities have been designed for individuals with physical handicaps and do not address the specific needs of people with chronic mental disorders. Future research should address this issue.

-Ralph Fasano

The author provides a very thorough literature review of the advances and major issues facing psychiatric rehabilitation during this decade. Perhaps the paper's greatest contribution, however, is its concluding discussion and nine points about changing values and philosophy. While most of the field would agree to these points, our major challenge is moving these concepts from rhetoric to reality. Another way to say this would be that the decade of the 1980s proved community support is feasible--the 1990s must make it real. Time would be well spent in the seminar defining implications for the research, training and service delivery in each of these areas.

I believe more discussion or a revisiting of the definition of the target population is also warranted. We are often asked to broaden the definition of the target group; however, this has been discouraged most of the time by both the federal and state governments. We must reconfirm the definition and discuss the problems as-

sociated with serving a broader group of persons.

The author provides an argument for the complementary nature of rehabilitation and psychiatric treatment. While the argument is well stated, we need strategies for strengthening this notion beyond a comment about conceptualizing the models as complementary rather than competing.

The author raises the issue of gathering more empirical evidence to better define and evaluate case management. This argument has implications for a major activity in the field today. While I would argue with the findings of the Franklin Study, we need to give more attention to the definition and efficacy of case management. Additionally, we must better define the role of the case manager vis-a-vis supported employment and housing models. The dilemma of how many functions can one person carry out vs. how many persons does it take to "case manage" one person is a present and future problem. Also, implicit in this argument is the age old discussion of the **perjorative** nature of the term "case management".

In summary, the paper presents a balanced view of the major issues to be wrestled with in the coming decade many of which warrant a more indepth discussion.

-Martha B. Knisley

I liked the author's characterization of the goal of psychiatric rehabilitation as improving quality of life by assisting patients to assume responsibility over their lives and to function as actively and independently in society as possible; I especially support his acknowledgement that "bad" treatment is treatment that does not involve the client; it is obvious to me that there can be no investment in psychiatric treatment if the people with mental illness are not consulted and included. In addition, primary mental health consumers--direct recipients of mental health services rather than their family members--should be incorporated in program development and evaluation.

Vocational training, supportive employment, and competitive employment are extremely important in the recovery process. Initial skill development is crucial for many persons with mental illness, especially in terms of developing a level of interpersonal comfort and an ongoing sense of self-worth and self-confidence. Programs should be designed to strengthen an individual's skills by building on personal assets, ensuring the best change of success in the community. A continuum of coordinated services must be available. We must find clinicians who are sensitive, empathetic, and compassionate.

Professionals and others must be enlightened so that they understand that persons with a mental illness are neither continuously nor always flagrantly symptomatic. Recipients of mental health services and family members should educate lawmakers about mental illness and the needs of the mentally ill, especially in terms of the current lack of community resources and inadequate funding for psychosocial rehabilitation. We must develop a system of mental health care where the dollar follows the patient. In addition, consumer and family involvement in comprehensive psychosocial rehabilitation is crucial to success. National Alliance of the Mentally Ill has become the major voice of relatives of persons with mental illness, but I believe the key to successful rehabilitation lies with listening to the primary consumer, the direct recipient of mental health services.

-Esso Leete

Anthony has done a masterful job of sketching out the modalities necessary for successful rehabilitation for most, but not all, of the chronically mentally ill population. Reframing rehabilitation as a positive and proactive substitute for the passive activity of depopulating hospitals is a paradigm that appeals to all of us. It is particularly appealing to mental health staff, to clinicians-in-training, and to legislators who want to vote funding for remediation, not containment, of an important social problem. The areas outlined are the critical ones, of course: daily living skills; job training and placement; social/recreational needs; and case management. There is also an ill-defined category called "rehabilitative residential services," which presumably means decent living arrangements which optimize the person's capability for living normally and doing things for himself or herself. The major points Anthony makes are critical ones and I wholeheartedly agree that rehabilitation and treatment are not necessarily competing models. On the contrary, I do not see them as discrete, but rather as an integrated process in which rehabilitation is an essential therapeutic modality, particularly when combined with supportive group therapy and/or a peer support group which offers the potential for taking charge of one's own affairs. By now it must be obvious to most clinicians that social and vocational activities which reinforce self-confidence through actual performance, are preferable to the introspective therapies of former years. Conceptual clarity is surely needed in the field to define parameters and distinctions in the array of interventions which are believed to benefit people with mental illness.

I feel it is misleading to counterpose deinstitutionalization and rehabilitation as dichotomous and mutually exclusive conditions. In fact, since the one is described as focusing on buildings and the other on persons, they are really not in the same domain. Institutions provided a total sheltered environment for the most severely disabled, a situation for which we have not yet found viable alternatives in the community. There is increasing evidence that there may be a subset of adult mentally ill persons who continue to need the concept and reality of asylum (Bachrach, 1984; Lamb, 1982). The danger of counterposing institutional living and rehabilitation is the suggestion that a mentally ill person can be functional only when living in the community. Does this mean that those who are incapable of living independently are not worthy of being rehabilitated to the greatest extent possible for them? Is there a danger of repeating the sins of community mental health centers,

which until recent years shortchanged the most needful to serve those more capable of showing progress (Lefley, 1988).

When one considers the world of severely mentally ill people, many of them organically impaired, Anthony's model raises a host of questions. Is every mentally ill person rehabilitable within these defined parameters? Will those who do not fit this paradigm--those likely to be most severely disabled and therefore most needful--be given short shrift because they do not meet the requirements of the model? (See Wasow, 1986). Will community rehabilitation programs continue to limit their services to motivated clients who are nonviolent, non-substance abusing, non-socially offensive, and non-regressed? For those few who do take the more dysfunctional clients, are there dangers of imposing toxic environmental stimulation--a "total push" effort which research has demonstrated may well be countertherapeutic for persons with the core deficits of schizophrenia (Wing, Bennet, & Denham, 1964)? And most important, is there a danger in the conviction and aggressive efforts of the rehabilitation ideology of conveying disappointment to those who cannot meet our expectations; of our being unable to accept people as they are and where they are without diminishing them as human beings?

Research, consensual definitions, and policy decisions regarding service priorities are needed to answer still more questions. These relate to what is most beneficial for the majority of seriously mentally ill persons. What percentages of mentally ill persons are potentially rehabilitable in terms of competitive employment, continuing education, independent housing, or similar operational measures of successful adaptation to non-institutional living? Can rehabilitation take place only outside of the institutional setting? Does the rehabilitation paradigm favor independent as opposed to congregate living? Can it adapt itself to a quasi-institutional or sheltered environment as well? Is rehabilitation possible even when some measure of supervision is indefinitely required? How much independence is optimal? Is independent living countertherapeutic in some cases? How can rehabilitation programs attract persons who are too functional for day treatment programs, but not functional enough to work?

While it will surely be argued that rehabilitation is tailored to each person's baseline behavior and potential for independent functioning, will minor increments in levels of functioning be acceptable to funding sources and legislative initiatives for services? If rehabilitation is counterposed to deinstitutionalization, does this mean that dollars will now go only to non-institutional programs? What happens to those most likely to need periodic hospitalization and least likely to show rehabilitative progress?

These comments are based on the premise that there must be a multiplicity of models for rehabilitation of the mentally ill. Although Anthony has presented the consensually defined criteria for persons who are severely psychiatrically disabled, we know that within that category there is great variability in symptomatic and functional levels, and in personality characteristics which affect acceptance of interventions and capacity for relapse and recidivism. It seems restrictive to limit rehabilitation to the community setting when the reality is that mentally ill persons are not always in the community. Rehabilitative efforts must begin in the institutional setting and in some cases the techniques will continue in that setting without losing validity. Behavioral techniques such as the social learning models of Paul & Lentz (1977) are as rehabilitative in the institution as the PACT program is in the community. And in fact, without that preliminary training it is doubtful that effective skill-building work can be done after discharge. Conversely, rehabilitation may require vigorous outreach efforts to persons who are in the community but outside of the mental health system: the homeless, the boarding-house dwellers, the substance abusers, or those who eschew contact with the system.

The major point in these comments is that rehabilitation of people with mental illness must focus on the marginal and more disabled groups as well as on those individuals who presently fit into our psychosocial rehabilitation programs. In order to provide legitimate alternatives to institutional care, we must have in place comprehensive community programs that are well-coordinated, flexible, and geared to a whide range of functional capabilities. As a nation, we do not presently have that capability. Until we do, we cnnot begin to speak of deinstitutionalization and rehabilitation as mutually exclusive realities.

There are some social policy implications in Anthony's counterposing of deinstitutionalization and rehabilitation in which the focus is on programmatic, training, research, legislative, and service initiatives that will enhance the rehabilitation model.

1. Rehabilitation and traditional psychiatric treatment (chemotherapy and supportive psychotherapy, as needed) should not be considered discrete categories but rather a seamless process of therapeutic intervention. Within this process, opportunities for consumer-run programs should be maximized to provide role-modeling and peer support groups for socialization. To effect these objectives in traditionally-run, publicly funded aftercare facilities requires outreach to program directors, directives from state mental health authorities and/or monetary incentives for specific types of service delivery and inservice training.

2. Professional staff in most community agencies have been trained in a psychodynamic psychotherapeutic model, which ill serves the seriously mentally ill population. They need updating on state-of-the-art etiological research and retraining in rehabilitation philosophies and techniques. The public, too, has to be educated on the parameters of rehabilitation as an effective tool for community integration of psychiatric patients.

3. We need research funding initiatives, Requests for Proposals from the National Institute of Mental Health and other interested sources for long-range studies of rehabilitation technologies. Longitudinal impact of case management, relationship of resources to outcome, types of vocational placements that are most successful, cost-effectiveness studies of rehabilitative and "treatment" approaches, and the match

of client characteristics to rehabilitative modalities are examples of needed research.

4. Legislation is needed to reinforce the rehabilitation model by providing funding for demonstration projects, housing alternatives, and service delivery. Legislatures may be lobbied to mandate relevant inservice training and continuing education for professionals working with seriously mentally ill patients in publicly funded facilities. Above all, we need a range of residential models which are self-sufficient for clients' needs and/or are linked to a range of external rehabilitative programs.

5. Critical changes are needed in existing service delivery models, which are derived primarily from the original Community Mental Health Center mandated services. Although there is a continuing need for crisis intervention, inpatient, outpatient, and day treatment services, they are largely based on older models of clinical treatment. Case management, socialization programs, and consumer-run alternatives require going beyond the clinic walls out into the community. Meaningful surveys and outreach efforts are needed to assess and serve the needs of mentally ill persons who have viewed the system as inaccessible or unacceptable.

6. As Anthony indicates, consumer input is required at all levels of the planning process. Consumer advocacy is needed as well. NAMI and primary consumer groups may be enlisted as a grass-roots constituency to influence the public and legislatures to require a rehabilitation model in publicly funded mental health facilities. Above all, we need to effect changes in the training of clinicians to serve the seriously mentally ill population. To this end, new curriculum tracks and disciplinary specializations are needed in basic clinical training in all core professions, as well as in sub-professional training of mental health workers. We need initiatives through professional organizations, as well as stipends and other financial support, to re-orient clinicians of the future toward a rehabilitation model for psychiatrically disabled persons.

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-Harriet P. Lefley

The effects of deinstitutionalization will be felt in the field of rehabilitation for many years. The era of the 1990s will be faced with all of the issues mentioned in this paper and more. Of special concern is the housing issue. Alternative housing conditions are pivotal if an adjustment to society is expected. Presently, there are not enough halfway houses or 3/4 way houses available to provide needed services for the psychiatrically disabled. Periodic hospitalizations serve to act more as a setback and are more costly to all concerned.

Although many psychiatrically disabled persons live with family members, there are many that don't. Without adequate support services and appropriate housing, they fall prey to people in a low-income environment. The result is oftentimes institutionalization of a different sort ... prison. Without preventive measures, many people will spend years in an institution where they do not really belong.

Independent Living Centers must be willing to address the needs of persons with psychiatric disabilities. A supportive living situation will be a great aid in helping the rehabilitation professional and the client to develop a rehabilitation program which will enable rather than disable.

-Robert J. Neuman

I certainly could not agree more with Anthony's statement that, "As we move to the decade of the 1990s, we need to talk less about deinstitutionalization and more about rehabilitation" (p.2). We need to be able to clearly define what rehabilitation practice is as regards to persons with long-term mental illness. We need to be able to discriminate between psychiatric rehabilitation, psychosocial rehabilitation, and vocational rehabilitation. For example, is psychosocial rehabilitation a social club, with the milieu as the only active intervention ingredient? Or, is psychosocial rehabilitation itself an active treatment intervention, with skill building at its core? Global statements do not answer the questions of program administrators, funding sources, or consumers. In defining the population served by psychiatric rehabilitation, we must be sure to acknowledge the person with chronic mental illness who is functioning well. Our definition should not equate chronic mental illness with dysfunction, and thus deny the seriousness of the illness given a person currently coping. Finally, during the 1990s, we need to continue working for the acceptance of psychiatric rehabilitation practice by the traditional rehabilitation community--by the state rehabilitation agencies, by state rehabilitation counselors, and by rehabilitation counselor educators. "It's not rehab if it's not vocational" remains the battle cry.

-Catherine A. Marshall

Dr. Anthony has presented a comprehensive picture of the status of psychiatric rehabilitation. He described: the contrast of deinstitutionalization versus rehabilitation; the definition of both

psychosocial rehabilitation and the population who is served by this approach; the complementary nature of the community support system initiative; the development of case management and the consumer and family movement; the ability to now replicate programs and provide training curricula, and the beginning work of empirical studies. Dr. Anthony has well articulated the crystallization of psychiatric rehabilitation in this decade. As the popular advertisement states, "You have come a long way, Baby!"

This reviewer well remembers the excitement of finding the theoretical framework of psychosocial rehabilitation at a NIMH Staff College on deinstitutionalization in the early 1980s. For this reviewer, the framework provided an explanation of program services she had developed and established at that time. In addition, it provided her a philosophical base for all future development and implementation of program services. also, it served as a foundation for program development for persons with other disabilities (multi-handicapped, hearing-impaired), not only those with mental illness.

Dr. Anthony's call for the conceptualization of treatment and rehabilitation models as bedfellows is a step in the right direction, that is, these models can exist as complementary as opposed to competing. However, many mental health service systems still have a long ways to go in committing to and funding a community based, client-centered system. The question remains as to how these systems will be persuaded to redirect their resources and philosophies.

Case management now also has a significant role in serving those with mental illness who are homeless and those who have substance abuse, especially the young chronic group. Is it the panacea for these populations or is it the only viable service that can be offered when facing the frustration of serving such difficult populations in the absence of both sufficient and new treatment or rehabilitation program modalities? This is another area for study.

As to the movement of psychiatric rehabilitation into the 1990s, can the sensitivity and the humanity conceptualized, and perhaps hoped for by the author, serve as the underpinning for the continuing development and funding of community-based programs, or will system funding decisions still be strapped between inpatient versus community-based services? Will acceptance of mentally ill persons by the community-at-large be at the level which will permit Anthony's 1990s concept of humanity become a reality?

Where are special populations in this movement? Services for mentally ill deaf persons are characterized on a continuum of sporadic existence of service components to the total absence of accessible services. The huge gaps in service provision portray a service system anywhere from one to three decades behind. Accessibility for deaf persons demands:

1. fluent skills in sign language and knowledge of psychosocial aspects of deafness by service providers, and

2. physical accommodations such as teletypewriter devices for telephone communication; flashing signal lights for phone, smoke detection, and doorbells; decoders, etc.

Presently, there are approximately 25 to 35 inpatient units, 30 to 40 outpatient units, and a dozen group homes for deaf mentally ill persons in this country, not even enough for one of each services for each state. Currently, mental health systems are still struggling to establish both inpatient and outpatient treatment services for deaf persons at a time when the national trend is for community-based programs. This seems backwards. With the absence of program services, program developers should grab the opportunity to initiate programs for special populations first within the community as opposed to hospitals.

Of special interest is the author's description of "impaired role functioning." The criteria described not only those deaf persons who are mentally ill served by this reviewer's agency, but also other disadvantaged deaf persons who are not mentally ill and served by the same agency. These criteria include: unemployed or underemployed, dependency on entitlements, inadequate social support systems, deficits in life skills and inappropriate social behavior. This reviewer has found that the philosophy of psychosocial rehabilitation has worked well when applied to a broader disability group within the deaf population, not only those with mental illness.

Case management has become extremely critical in serving deaf persons with mental illness because of the multiplicity of their needs and the inaccessibility of programs; however, as Anthony notes, case management is only as effective as the number and types of resources that are accessible and available to the service population.

-Carole Schauer

Dr. Anthony's paper sets the tone for the 12th Switzer Seminar by contrasting the era of deinstitutionalization (and its failures) with the promise of the emerging era of rehabilitation. By thoroughly reviewing the literature he focuses on conceptual pragmatic and empirical developments characterizing the 1980s and preparing the path for the 1990s.

Considerable progress has been made in the field of psychiatric rehabilitation as a result of better, more clearly articulated principles and ideology. Conceptually, definitions of rehabilitation services consistent with the values of the National Institute of Mental Health Community Support System initiative; agreed upon definitions of the population to be served (those with a diagnosis of severe mental illness of prolonged duration with function or role incapacity; the development of replicable program models (the "clubhouse" and PACT [Program of Assentive Community Treatment]; the teaching of specific skills to practitioners; the maturation of the concept of case management as the need for a caring person to guide people with disabilities through the rehabilitation process; the development of supported employment services; have all laid a foundation for

beginning efforts at empirically proving the worth of rehabilitation.

This literature review reveals that psychiatric rehabilitation positively impacts significant outcome measures such as recividism, time in the community, employment and productivity, skill development and client satisfaction. Family psychoeducational interventions reduce rates of relapse as well.

Dr. Anthony emphasizes the complementary (rather than competing)nature of the treatment and rehabilitation models with a focus on client and family involvement. It is clear that the policies of the 1990s must explicitly define the mission goal of service programs to provide a client-centered system which maximizes the opportunity for persons who are disabled to function as independently as possible in living and working environments of their choice, with the level of support and services they need to do it.

Marye L. Thomas

Scenes from the Seminar

Neal Brown, Jacqueline Parrish and Paul Carling (l to r)

Dr. Irving King Jordan, President Gallaudet University

James R. Burress and Carl E. Hansen (l to r)

Housing and Support for People with Psychiatric Disabilities:

Directions for the 1990s

Paul J. Carling

During the past 30 years there has been a dramatic shift in the focus of treatment and support for people with psychiatric disabilities. Hospital treatment time has become shorter, and a wide range of community-based services has been developed. Only in the last decade, however, have we come to understand the importance of a stable and supportive living environment in helping people with psychiatric disabilities live successfully in the community. This is a problem of major scope: There are an estimated 1.7 -2.4 million Americans who can be considered as having "long-term mental illnesses" based on psychiatric diagnosis, severity of disability, and duration of disorder, and many of these individuals are inadequately or inappropriately housed or homeless. This review summarizes our current understanding of the problem of housing and community supports for people with psychiatric disabilities.

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Two recent reviews of the outcome research literature related to supporting people with psychiatric disabilities in local communities (Anthony and Blanch, 1988; Wilson, 1988) summarize many of the important learnings which should guide our thinking about improved ways to provide people with disabilities with decent housing and to support them on an ongoing basis.

These general learnings include:

1. Serious mental illness is not necessarily a life-long degenerative process.

2. Many people with severe mental illness, over the longhaul, can maintain jobs, friends, and families.

3. Mental health services must be highly flexible in order to be responsive to different individuals' needs: correspondingly, people with the highest level of disability seem to have the most individual needs. Paradoxically, we have tended to serve most disabled persons in congregate settings, perhaps for reasons of cost or administrative convenience.

4. People can make positive choices about the kind and intensity of support they receive.

5. Given choice, most people don't define themselves principally as "chronic mental patients," and they value independence and productivity more than any other treatment outcomes.

In terms of specific research related to housing, we find that:

1. Virtually all forms of community based residential treatment programs can substitute for inpatient treatment; there is no clear evidence that one program type is consistently more effective than any other.

2. Characteristics of environments (e.g., size) are more predictive of outcome than characteristics of residents.

3. Outcome is also related to clients seeing a match between the housing they're in, and the way they define their own needs.

On the other hand, there is almost no research on how to help people get and keep permanent housing, and almost no research on cost.

Without active rehabilitation, many people with psychiatric disabilities lack the skills and supports needed for successful community living. Emotional and behavioral problems and skill deficits due to long-term institutionalization may interfere with a person's ability to select and secure a desirable community living situation or to maintain it over time. In addition, the recurring nature of long-term mental illness may result in loss of housing as the person experiences repeated hospitalization (Bachrach, 1982; Budson, 1981; Carling, 1984; Carpenter and Bourestan, 1976; Chatetz and Goldfinger, 1984; Coulton, Holland and Fitch, 1984). Housing discrimination based on stigma is also a day-to-day reality. Many landlords simply refuse to rent to people with a history of mental illness, making it difficult to gain access to normal housing (Aviram and Segal, 1973; Hogan, 1984, 1985a,b; Segal, Baumohl and Moyes, 1980).

Moreover, many people with psychiatric disabilities are poor. Unemployment rates are high (Dion and Anthony, 1987), and all major entitlement and public assistance programs (including Supplemental Security Income, the major income maintenance program for this group) are set at levels which virtually guarantee that people with disabilities must live well below the poverty line. In addition, access to SSI has been seriously reduced in recent years, especially for young adults.

People with psychiatric disabilities must also compete for existing housing with other low income groups, including new immigrants, students, single parent families, and the "working poor," all of whom are generally viewed as more suitable tenants. At the same time, the stock of low-income housing is shrinking rapidly. According to a recent study, the shortage of affordable housing has increased by over 2.15 million units, or 120 percent, since 1980 and only a very small number of these units are replaced each year (Low Income Housing Information Service, 1986). This trend appears to be the major cause of homelessness nationally.

During this same period, public sector support for housing subsidies has sharply declined. The return of young professionals to urban living has resulted in the "gentrification" of many metropolitan areas, and condominium conversion and upscaling of urban real estate has caused rents to skyrocket. In addition, many middle class families have been priced out of the housing market, and have been forced to remain as renters rather than purchasing a home. Finally, the increase in divorces, never-married persons, and elderly persons living alone has increased the overall number of households (Low Income Housing Information Service, 1986). It is little wonder that individuals with disabilities fare badly in such a housing market.

The consequences of not attending to people's permanent housing needs have been severe. Many people with psychiatric disabilities remain as patients in psychiatric hospitals because of the lack of stable housing. (Toward A National Plan, 1980). Others cycle through emergency rooms and are admitted to general hospitals (Coulton et al., 1984). Such hospital stays are costly and often inappropriate (Braun, Kochansky and Shapiro, 1981; Chatetz and Goldfinger, 1984; DHHS, 1983; Geller, 1982). Many other individuals, both young and old, have been relegated to long-term care environments such as nursing homes and boarding homes. Most of these settings lack an active rehabilitation or treatment orientation, and can lead directly to declines in functioning (Kohen and Paul, 1976; Lamb and Goetzel, 1971; Minkoff, 1980; Oriol, 1980; Segal and Aviram, 1978; U.S. Special Committee on Aging, 1976; Wolins and Wozner, 1982).

The lack of permanent housing options for people with psychiatric disabilities has also resulted in substantial family burden (Doll, 1976; Hatfield, 1984; Kint, 1978; Spaniol, Jung, Zipple and Fitzgerald, 1984; Wasow, 1982). In the early days of deinstitutionalization, nearly two-thirds of all long-term patients returned to their family home upon discharge. Today, perhaps one-third of those who leave psychiatric hospitals return to live with their family of origin. In addition, many severely disabled young adults who have never been hospitalized require substantial support to remain in the community. Families are thus often forced to serve as case managers and as landlords with little support from the mental health system.

Of those individuals with psychiatric disabilities who do find independent housing situations in the community, a high proportion end up in very low-income neighborhoods. Substandard housing and high crime rates are typical in these areas, and "oversaturation" of neighborhoods with disabled people often leads to community backlash against deinstitutionalization (Apte, 1968; Carling, Daniels and Ridgway, 1985; Coulton et al., 1984; Segal and Aviram, 1978).

Finally, an increasing number of people with psychiatric disabilities are homeless (Arce, 1983; Bassuk, 1983; Baxter and Hopper, 1981, 1984; Leaf and Cohen, 1982; Levine, 1984; Mowbray, 1985). Psychiatric symptoms and/or a history of hospitalization characterize perhaps one-third of all homeless Americans, although estimates range well above 50 percent (Bachrach in Lamb, 1984). Homelessness is a complex problem with multiple causative factors, including unemployment, the dearth of low-cost housing, and recent cuts in government benefit payments (Bassuk, 1984; Frazier, 1985). Among individuals with psychiatric disabilities, some homelessness has resulted from poorly organized deinstitutionalization efforts (Lamb, 1984). Community mental health systems have generally not responded effectively to the needs of homeless people (Caton and Goldstein, 1984). Instead, emergency shelters have flourished, offering only a stop gap approach to resolving the problem (Lamb, 1984; Bassuk, 1983). Rather than shelters and psychiatric or social services, homeless people with psychiatric disabilities often indicate the need for permanent, affordable housing along with financial supports or other legitimate sources of income. In general, then, homeless people who are mentally ill need housing, financial help, employment opportunities, "contact" services, and rehabilitation (Lipton and Sabatini, 1984). They also need services which are culturally appropriate to their needs (Segal and Baumohl, 1980).

Historically, mental health agencies have viewed housing as a social welfare problem, and have defined their role narrowly in terms of "residential treatment." Similarly, public housing agencies, and in fact the general public, believing that mental health consumers need some sort of "specialized residential programs," see their housing needs as a mental health responsibility (Carling, Daniels and Ridgway, 1985).

As a result, housing needs have been largely ignored, and most of the early residential development in the mental health field was not designed to offer people a stable living situation, but rather provided programs or therapeutic settings, typically time-limited. Transitional "halfway houses" geared to easing the move from hospital to community living began to proliferate in the early 1960's. Halfway houses did not meet all needs, however, and service providers soon came to recognize the need for a range of living environments.

As residential programs with different levels of structure and intensity were developed, providers began to think in terms of a "continuum" of residential services organized developmentally or functionally. Some elements of the "residential continuum" have included "quarterway houses" offering preparation for community living, often in a facility on hospital grounds; "halfway houses" with an emphasis on group milieu and skills development (Budson, 1981; Glasscote, et al., 1971); "three-quarterway houses" with less intensive staffing than "halfway houses" (Campbell, 1981); "family foster care" in which alternative families are used as a transitional support as people leave the hospital or as longer term housing (Carling, 1984b); "crisis alternative models" including family-care, crisis residences, special apartment settings, or intensive outreach to any setting in which a person in crisis resides (Polak, 1978; Stein and Test, 1980, 1985; Test, 1976, 1981); "group homes" which are congregate living situations that range from custodial boarding home settings to intensive treatment-oriented transitional residences; "Fairweather Lodges" for a small group of patients who move out of the hospital to live and work together on a long-term basis (Fairweather, 1980; Fairweather, Sanders, Maynard, and Cressler, 1969); "apartment programs" termed "supervised apartments," "semi-supervised apartments," "cluster apartments," "cooperative apartments," and "independent living" which may involve live-in staff, staff living nearby or visiting staff (Carling et. al., 1985; Carling, 1978; Goldmeier, 1975; Goldmeier, Mannino and Shore, 1978; Goldmeier, Shore and Mannino, 1977); "boarding home," settings in which ex-patients receive room (boarding homes, single room occupancies or SRO's, rooming houses) or room plus meals and/or services, (board and care, residential care facilities) (Carling, 1984a; Kohen and Paul, 1976; Lamb and Goetzel, 1971; Segal and Aviram, 1978); "nursing homes," to which large numbers of patients were inappropriately transferred and remain; (Carling, 1981); and "shelters for homeless persons" which provide overnight lodging for individuals and, in some cases, families (Bachrach, 1984; Leaf and Cohen, 1982).

Problems with Relying on Residential Programs to Provide Housing

Despite the recent growth of residential services and the emergence of new program models, there is growing evidence that residential programs do not, *per se*, meet housing needs. In the last several years, in fact, serious questions have been raised about the tendency to confuse residential treatment and housing needs, or to assume that people generally need to participate in such programs prior to "independent living". These questions have emerged from several diverse developments, including the growing acceptance of a rehabilitation approach, and learnings from other fields.

Recently Dion and Anthony (1987) completed a comprehensive review of the literature on psychiatric rehabilitation. This review summarizes the research support for the essential elements of a rehabilitation approach:

1. the critical importance of client goals;
2. the need for an individualized functional assessment which focuses on the characteristics of the person within the specific context of those environments in which the person must function;
3. the need for training focused on developing the specific skills necessary for success in those environments;
4. the importance of developing supports and resources which will assist the individual to function as independently as possible from formal helping systems.

Their research review also summarizes the finding that these critical elements are not routinely available in most programs.

A range of research and training activities undertaken by the Center for Change's Community Residential Rehabilitation (CRR) Project has also revealed significant dissatisfaction among consumers, their families and service providers about current assumptions and practices in this area. Those concerns focus on the limited usefulness of such concepts as a "residential continuum," and serious problems with the predominance of a "transitional services" model. Randolph et al. (1988), in a summary of the Project's learnings, point out that one danger in the concept of a continuum is that it is often implemented in a rigid way with inflexible time limits.

In many cases, the simplistic notion that a person can be given "transitional" help through a series of time-limited stays in specialized residential settings, in order to achieve "independent living," has resulted in major difficulties for the person with a psychiatric disability including: 1) having to adjust to pre-determined programs rather than individualized services; 2) chronic dislocation through successive moves; 3) an ultimate return to family, boarding home, hospital, or homelessness due to the inattention of most treatment-oriented systems to the implementation of the final stage of the "continuum" -- assistance in securing permanent community housing. A "residential continuum" usually places heavy emphasis on separate residential facilities, rather than the services and supports people need to function successfully in normal housing. In many programs, it is assumed that growth in functioning should also be associated with a physical move from one setting to another. Many "transitional" programs emphasize skills that apply either to a group living environment, and are therefore less relevant to living independently, or emphasize skills which cannot be easily transferred to another setting. In summary, the "transition" and the "continuum" concepts often confuse the need for housing with the need for specific supports and, in effect, makes receiving housing completely dependent on participation in a service program (Randolph et al. 1988).

A final area of controversy concerns the role of consumers themselves in determining the need for housing and supports. In a county-wide needs assessment, the CRR Project gathered

data from both providers and consumers as to their perceptions of the need for housing and supports (Daniels and Carling, 1986). Results indicated very substantial disagreement between professionals and consumers, with professionals favoring transitional, highly staffed residential programs for the great majority of consumers, while most consumers expressed preference for normal housing with flexible supports. Further, most consumers preferred to live with one other person, rather than alone or in a larger group. These results suggest that careful and critical evaluation and planning should be pursued before residential program development continues.

Until very recently, the notion of creating a large number of facility-based treatment options for people with psychiatric disabilities continued to dominate the mental health field. In the past few years, however, the field of mental health has been increasingly influenced by approaches to meeting the needs of other groups who require special supports in their housing: people with low incomes, those who are elderly, people who are homeless, and those who have developmental disabilities and/or mental retardation. In a recent comprehensive review of the research related to housing and community integration for all disability groups, Carling, Randolph, Ridgway, and Blanch (1987; 1988) summarized some applicable findings. This review concluded that:

1. Housing needs are similar for each of these groups. Support needs are more varied, although there are some common needs, including income supplements, transportation and so forth. Supports appear to be the critical factor in whether or not people can remain in a housing situation of their own choice.

2. Housing problems are less closely related to disability than they are to economic and social factors such as poverty, the decline in affordable housing stock, and discrimination.

3. There are substantial differences of opinion between professionals and consumers about specific needs for housing and supports, regardless of which disability group is involved.

4. Choices and control over one's environment are critical necessities regardless of special need. Consumers must therefore be centrally involved in planning their own housing and support services, and should have the opportunity to manage their own services.

5. Because of the lack of in-home supports and services, elderly and disabled people are plagued by transience, dislocation and the risk of institutionalization.

6. The model of a "residential continuum" is increasingly beset by conceptual and practical problems.

7. The disability field in general increasingly emphasizes normal housing and the need to avoid transforming housing into service settings.

8. Community integration approaches increasingly avoid congregation and segregation, and instead focus on building relationships between disabled and non-disabled individuals.

The learnings from the community support and rehabilitation literature in mental health, and in these other fields, suggest that the key ingredients of community integration are a focus on consumer goals and preferences, an individualized and flexible rehabilitation process, and a strong emphasis on normal housing (Blanch, Carling and Ridgway, 1987; Carling, Randolph, Ridgway and Blanch, 1987; 1988). In the field of mental health, this approach has been termed "supportive housing" (NIMH Guidelines, 1987; NIMH CSP Services Demonstration Grant Announcement, 1987).

Planning, Financing and Providing Supported Housing within a CSS

The field of "residential services" is growing at a remarkable rate. The Center for Community Change's National Survey of Community Residential Programs has identified almost 2,400 publicly funded or licensed agencies operating more than 4,500 residential programs for people with psychiatric disabilities, excluding board and care homes and other private facilities (Randolph, Carling and Ridgway, 1986, Randolph, Ridgway and Carling, 1988). In fact, over 50 percent of all residential programs operated by CMHC's have been started since 1980 (National Council of Community Mental Health Centers, 1984). Forty-five out of fifty states recently reported being actively involved in developing residential services as a high priority, and over 65 million state and federal dollars were spent on non-hospital residential alternatives during fiscal year 1985 (Ridgway, 1986).

Residential services are principally a state responsibility. The Center's survey data also suggest that over 70 percent of residential services are funded through state mental health funds. In 1984, the National Association of State Mental Health Program Directors (NASMHPD) developed a policy statement that provided the first nationwide state mental health agency commitment to meeting the housing and support needs of adults with prolonged mental illness. In part this policy states:

> It is the responsibility of state mental health authorities to take the lead role in addressing (housing) needs, advocating for improving the housing situations of these clients, and developing specialized residential services for them. (NASMHPD, 1984).

In spite of this growth, estimates of the number of people with psychiatric disabilities who reside in such programs vary from only two to five percent in various systems (Ridgway and Carling, 1988). The expense of residential programs in relation to the small numbers served shows clearly that residential programs cannot (and should not) serve as stable housing, and has encouraged planners and advocates to begin distinguishing between developing residential programs, and supporting people in their housing regardless of where they live.

NASMHPD recently approved a policy statement that sharpens their focus even more clearly and endorses the concept of "supportive housing." It reads:

Housing Options

> All people with long-term mental illness should be given the option to live in decent, stable, affordable and safe housing, in settings that maximize their integration into community activities and their ability to function independently. Housing options should not require time limits for moving to another housing option. People should not be required to change living situations or lose housing options when their service needs change and should not lose their place of residence if they are hospitalized. People should be

given the opportunity to actively participate in the selection of their housing arrangements from among those living environments available to the general public. Although public mental health systems need to exercise leadership in the housing area, addressing housing and support needs is a shared responsibility and requires coordination and negotiation of mutual roles of mental health authorities, public assistance and housing authorities, the private sector, and consumers themselves.

Provision of Services

Necessary supports, including case management, on-site crisis intervention, and rehabilitation services should be available at appropriate levels and for as long as needed by persons with psychiatric disabilities regardless of their choices of living arrangements. Services should be flexible, individualized and provided with attention to personal dignity. Advocacy, community education and resource development should be continuous. (NASMHPD, 1987).

State mental health program directors are clearly taking the lead in addressing the supported housing needs of people with psychiatric disabilities, and are doing so with full recognition that housing is only one of a number of necessary community support services. In order to implement this approach, however, mental health systems will need to engage in substantially different kinds of planning, financing, program development and human resource development activities than they have conducted in the past (Carling and Wilson, 1988).

Implementing a Supported Housing Approach

The many social, economic and personal barriers that face people with psychiatric disabilities who are trying to live in normal community housing have been reviewed in earlier sections. The Center for Community Change, in its work with mental health systems, has begun to identify significant barriers which block a system's capacity to implement a supported housing approach.

The first and most critical barrier is the lack of understanding that client choice is the most essential element of this approach, and that "supported housing" is simply infeasible unless clients are actively involved in defining their own needs and preferences from the start. There is ample evidence that consumers and professionals differ widely in their perceptions of needs and treatment goals. For example, in a county-wide needs assessment, the CRR Project gathered data from both providers and consumers as to their perceptions of the need for housing and supports (Daniels and Carling, 1986). Results indicated very substantial disagreement between professionals and consumers, with professionals favoring transitional, highly-staffed residential programs for over three-quarters of their clients, while over three-quarters of the clients themselves expressed a preference for normal housing with flexible supports. Further, many consumers seem to prefer to live with one other person, rather than alone or in a larger group, although a small number express a preference for shared living, typically without staff.

Based on the experience of the Center for Community Change, mental health systems generally attempt to plan and develop "supported housing options" without questioning their own assumptions about what options should be available. This approach will inevitably result in the expansion or refinement of the same kinds of programs and services developed in the past, subject to the many problems described earlier.

There are a number of reasons why mental health systems often neglect this critical feature of the supported housing approach. There are often attitudinal barriers, with some people simply not believing that people with serious long-term psychiatric disabilities can make good choices, identify their own needs for support, or participate in bureaucratic planning functions. This problem is compounded by the pervasive sense that housing is a complex and technical field, requiring the participation of highly specialized professionals. Although housing financing and development are certainly complex, every actor involved in a real estate transaction understands that the customer's needs and preferences must drive the entire process. The same should be true in the development of supported housing services.

History and habits of response also contribute to the exclusion of consumers and ex-patients from most planning and policymaking endeavors. In most areas, mental health consumers have never been involved in any substantial way in determining service system policies or priorities, so it simply doesn't occur to people that they ought to be. And as with any new endeavor, people need assistance with the details of implementation, such as how to ensure representativeness, what kinds of special supports are needed (e.g., transportation to meetings; stipends; how best to structure input; and so forth).

The second major barrier to effective implementation of a supported housing approach is the lack of understanding of the implications of this approach for the daily operations of mental health administrators. In working with states, it seems clear to Center staff that, in order to implement supported housing in anything more than a token manner, virtually every aspect of state mental health administration may need to be modified. Financing mechanisms must be altered, budgets restructured, human resource development efforts redirected, MIS databases redesigned, quality assurance and monitoring procedures reconceptualized, and so forth. These administrative structures develop, maintain and monitor all mental health services, and they are not currently designed to support services which are truly integrated in the community. If the key managers of the mental health system do not see the implications of the supported housing approach for their own operations, any change which does occur will be superficial and probably temporary.

Those states which have made the greatest strides in implementing a supported housing approach have undertaken a systematic process to re-examine and restructure their current operations.

In early 1988, NIMH convened a meeting of state mental health leaders, financing experts and consumers, all of whom were involved in innovative approaches to meeting housing needs. The purpose of the meeting was to discuss practical strategies for expanding housing and supports for people with psychiatric disabilities. The recommendations from that

group (Carling and Wilson, 1988) were far reaching. They are organized below according to the principal elements of supported housing (normal integrated housing, consumer choices, support services, and finances). These recommendations are summarized here as directions to suggest practical ways through which the mental health field can better meet housing and support needs in the future.

Recommendations for Promoting the Use of Normal Integrated Housing:

1. The mental health field as a whole should move toward defining clear outcomes with regard to housing and supports.

2. Research should be significantly expanded which demonstrates effective strategies for helping people succeed in regular housing with supports.

3. Mental health systems have a responsibility to promote "supported housing" values and approaches at the local level, through training in individualizing supports, working with landlords and the housing industry, and so forth.

4. States need to forge partnerships with local groups which represent overlapping interests, such as neighborhood development and revitalization groups, and then use these partnerships to expand housing for people with low incomes and disabilities.

5. State and local mental health systems need to develop the capacity for expertise in financing and development. How this function is operationalized will vary depending on the characteristics of each system. A key function is to serve as "broker" between the various constituencies and the mental health and housing fields, so that representatives of both fields can collaborate effectively at both local and state levels.

6. Mental health systems need to assure that their financial structures and rules promote the use of normal housing, rather than the development of facilities. These financing mechanisms are best oriented toward increasing clients' income, promoting access to regular housing, and home ownership.

7. Systems should re-examine their management information systems to be sure they are collecting relevant information on where people live, their housing preferences, supports available to consumers and their families, and so forth.

8. States need to recognize that creativity and innovation in meeting housing needs will principally occur at the local level, and to encourage such experimentation, particularly through collaboration with the housing industry.

9. Mental health leaders should promote the understanding that the "supported housing" approach is not an entirely new direction. The vast majority of consumers already live in normal housing: the problem is that they and their families are not typically supported there, nor do they have many choices about where they live. Further, inadequate housing and supports undermine their ability to succeed in communities.

10. In "marketing" the use of normal housing, state leaders should be clear that the concept refers not only to generic housing, but also to housing which is responsive to the needs of people with mental illness (e.g. not isolated), housing which promotes relationships with people without disabilities, and housing in which consumers have access to the supports they need.

Recommendations for Promoting Consumer Choices:

1. Mental health leaders should aggressively create opportunities for consumer "voice" in every way possible, and then set an example on how to listen to and respond to this voice; similarly, strong efforts should be made to include family members and their perspective in every way possible.

2. Mental health leaders should prioritize expanding housing options, particularly based on what is currently missing; a key gap is increasing the income of people with disabilities.

3. Mental health systems need to view housing as housing, not as treatment; they need to examine architectural issues and explore how housing can promote integration.

4. Collaboration with other agencies is critical, especially those agencies which can assist with housing and jobs.

5. Mental health systems need to examine the extent to which their own financing and administrative rules limit consumer choices.

6. Systems need to develop data on collective choices (i.e. consumer preferences), and also to incorporate expectations about individual choice in all programs, rules and so forth. A high priority should be placed on the development of tools and methods to gather data on consumer preferences, as well as the active consideration of this information in management decision-making.

7. Advocates should consider statewide coalition approaches, particularly with other low-income and disability groups.

8. A rehabilitation approach (Dion and Anthony, 1987) which stresses the need to help consumers choose, acquire and maintain housing through skills development and supports, is a powerful strategy for expanding consumer choices. Similarly, efforts are needed to help some consumers learn the skills involved in making choices, and in helping professionals develop more of a "marketing" approach with consumers, just as realtors do when their clients are looking for a place to live.

9. States should encourage close collaboration between consumers, family groups and service providers focused on developing a consensus about housing and supports.

Recommendations for Reorganizing Services to Support People:

1. Mental health systems need to focus on clarifying the kinds of service approaches and models which are responsive to our current knowledge about the needs of people with serious mental illness, and the importance of housing.

2. Systems should also use multiple incentives, or sanctions if necessary, to increase the responsiveness of current programs to their clients' housing needs, and to service provision approaches which will support clients in their housing. Where states are fortunate enough to be able to develop new services, these should be carefully designed to emphasize

responsiveness to these needs (e.g. continuous treatment teams, mobile services, other housing support services).

3. States need to make a commitment to a major retraining effort if services are to become more relevant and responsive. This includes changes in university disciplinary training programs. Salaries of support staff are also much too low, in general, given their importance to consumer success.

4. In order to promote innovation, states should provide resources to local programs which are based on goals or outcomes, rather than on specific methods of reaching those goals.

Recommendations on Restructuring Finances to Promote Supported Housing:

1. State mental health agencies need to increase their expertise related to housing finance and development, and to provide technical assistance on financing to local programs.

2. State and local systems need to expand the use of generic local housing development organizations and resources.

3. Since the value of consumer choice is critical, and consumer ownership highly desirable, systems should be cautious about encouraging provider agency ownership of property, and its impact on these values.

4. Systems need to stress the development of accountability mechanisms which reflect real improvements in consumers' lives.

5. States should be encouraged to develop housing subsidies for consumers to help them access better housing on a short term or long term basis.

6. States need to move to more flexible services reimbursement options which promote the routine availability of off-site services, such as through the rehabilitation and case management options under Medicaid.

Summary

In summary then, the supported housing approach represents a significant opportunity for mental health clients and public systems. Implementation of this approach poses significant challenges as well to mental health leaders, challenges which will require much great clarity of vision about how we can assist consumers to succeed in local communities, a sharper focus on the role and mission of public mental health systems in this process, and vigorous leadership to pursue this mission.

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Housing: A Crucial Dimension

Jerry Dincin

A major objective in the psychiatric rehabilitation movement must be creating opportunities for "independent living". To a significant degree this means providing housing, though to be sure, independent living means more than that. Since most community mental health centers do not take the provision of housing or the development in independent living as a top priority for their program, the most important decision for individual agencies is to make sure they see this as their business. It is their business. They need to make it their business.

There are, of course, many impediments and difficulties in making this happen. Foremost among them are single level approaches to what is "right" in housing. Is there a "correct" way or a "correct" style as some writers have indicated? or should many other approaches be considered and implemented? Should federal policies at NIMH strongly encourage one type of housing in preference to another? I believe this to be wrong for a number of reasons, not the least of which is that it limits creativity of the agencies and may not meet the needs of a particular locality.

To strongly emphasize one style of housing and denigrate others as the wrong approach, seems to be a false step and one with which I would strongly disagree. The most prominent example of this one-style approach is promoted with intensive vigor, and this is the one that would emphasize reliance on separate apartments, with individual or shared tenancy, in scattered sites. I believe it would be a monumental error for those in the field to strictly adhere to this approach. A *spectrum* of housing opportunities is needed with some modest reliance on the separate apartments mentioned above. It seems to me, however, that there is ample opportunity and need for group homes of various styles and types, foster care opportunities, clustered apartments, SRO's, Fairweather Lodges, boarding homes, and others yet to be invented. These different housing opportunities tend to serve different functions. Some have a rehabilitative emphasis, some have a more intensive treatment style, others are supportive, yet others are respite, or emergency, or crisis housing. No one housing style will fit for every mentally ill person. Rehabilitation can occur and does occur in all of the styles mentioned.

Clearly, there are some disadvantages to a scattered site long term housing approach. This can't be denied and they have been enumerated at length in the literature. It definitely reduces the need for capital funding, reduces or eliminates zoning and community opposition issues, and for a small number of clients, either those who are "best off" or "worst off", makes good clinical sense. However, the arguments against this approach are legion, especially by those long involved with housing on the front lines.

Let's get back to basics. The provision of independent living opportunities is crucial business for our field. It may offer the single best opportunity for personal growth for our members, but we must remember that people who have a psychiatric disability come in an enormous variety of sizes,

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types, and degrees of difficulty. I continue to be astounded by the variation in functional disability in the group. There are those who are in remission, and a continuum exists between those in remission and those with a persistent illness. There are those who have a mild case of mental illness, as well as those who have moderate and severe cases. We need to be wary of basing our decisions on limited experience with only one type. There are those who have infrequent exacerbations and those who have frequent episodic problems. There are those whose illness is mitigated by medication and a number of unfortunate people where it is not.

In my judgment, mental illness is not a learning deficit and classroom training will not seriously effect the illness itself, although it may have an impact on some people. No matter how much we teach activities of daily living in a classroom format, our members' illnesses remain resilient and resistive to that approach. Nor is mental illness in my judgment a social deficit in itself. It is not a crisis in self-confidence, although self-confidence is sorely lacking in many people who have mental illness. If we only go about restoring self-confidence with programs that emphasize strong member participation as their central concept, we miss the central point of what we are dealing with. I believe that at its center, its very essence, mental illness as expressed in schizophrenia, manic-depressive illness, and severe depressive illness, is a biological ailment of brain chemistry which, in turn, manifests itself as behavior, learning, thinking and emotional difficulties. So, first of all, we need to correct the biology with the tools at our command, then we need to accept that even when one's biology is relatively corrected, our members still have psychological problems that are responsive to human intervention by caring, empathic, sensitive professionals. In addition, there are a host of rehabilitation issues that need to be handled, and it is to that portion, the rehabilitation process, that we address the remainder of this housing paper.

What our members need in housing is a system with many options that is flexible and it should definitely not depend on one style of housing. My reasons for this follow:

1. No single approach could possibly be right for such a varied population.

2. While the use of a strict "continuum" of housing opportunity does have problems, the use of an "array" of housing does not. Flexibility is key.

3. Skill development is not the issue. Most members need a nurturant living situation that is best exemplified in a group home. The milieu that can be created in a group home is actually healing for many members. Every psychosocial rehabilitation agency believes in the importance of their milieu and they believe it makes a difference. It also makes a difference in housing. In particular, it offers a sense of belonging in a family-type communal living that may be frequently expressed in our culture in the style of a fraternity or college co-op.

4. There are many special populations where it seems unlikely that scattered housing would be a significant help. Conceivably, it could help the homeless, though with the huge number of homeless it seems monumentally unlikely that this approach could make a dent in this population. This group can and should be treated in a group setting--not one or two at a time. The 18- to 22-year-olds also need some special attention. Usually, this group needs some structure and limit-setting, not easily available in scattered apartments. The deaf mentally ill, among other special need groups, are best dealt with in a group setting since their illness itself is so isolative.

5. In my opinion, personal growth, particularly upon a recent release from a mental hospital does not occur best in a scattered apartment arrangement. In many ways, this emphasizes the loneliness instead of emphasizing the growth and interactive potential. How to encourage that growth in the most supportive way is a huge question that can't be answered for all people in the same way.

6. In my experience, although it is *theoretically* desirable for people with persistent mental illness to integrate their social lives with their neighbors, this is an almost completely unrealistic expectation. Who are we kidding? For this group of people isolation is a usual, though unwelcome, part of their illness. I do not see a lot of naturally gregarious people. For the most part, this group is too ill, too symptomatic, too disabled; and moving into an independent apartment is not the best way to overcome this.

7. Some question needs to be raised about what is so bad about consumers living together. Is there some subtle disrespect for consumers implicit in this argument? Really, why *shouldn't* these people live together? They need *peer* support. Friends that develop in mental health settings are frequently the only friends that they have. No one suggests that separate housing for the aged population is necessary to be integrated with that of the younger population. In fact, housing for the elderly is usually built separately. Wouldn't it be more "normal" for them to mainstream in the same way that is suggested for the mentally ill? Our experience is that members tend to stay together and form friendships partially because they like each other and such friends are available, and partially because it is extremely difficult to integrate oneself into the normal community except if you are quite recovered.

8. The scattered apartment approach involves an over-dependence on professional support that tends to negate the availability of peers in times of need or for company. Helping members develop friends in their natural peer support group is beneficial. It adds a sense of warmth and connectedness that is crucial.

9. While it is true that learning to cook for ten in a group home doesn't necessarily teach cooking for a single person, it is also true that there are some skills that are absolutely transferrable including budgeting, basic cooking techniques, cleaning, shopping, and bargain hunting that are generic to all people and can be learned in a group setting.

10. While it may be true that members ask for individual apartments, in my experience, it is usually because they are not aware that any alternatives exist. When they are apprised of alternatives, they are most willing to utilize them. An analogy could be made to members asking for full-time jobs when they are first referred to the agency. This is the request of 90 percent of our clientele, yet it is perfectly clear that the request itself is not sufficient and frequently their own evaluation of their capabilities are far from reality. Some things need to happen *before* a person goes on a job or *before* a person lives in a

scattered site apartment, otherwise we tend to recreate the same stresses that caused problems earlier.

11. There are many positive aspects of small group home living that cannot be easily accomplished in individual apartments, for instance, the availability of companionship without the necessity of intense intimacy; the availability of a variety of people with whom to try out new friendship and independence skills; the availability of some companionship when the member doesn't need professional help, but is still scared or lonely. For older adolescents in particular, a group home gives the opportunity to work on separation issues, control of symptoms, and developing effective interpersonal ability in a real setting with other people.

12. There is the implicit assumption in this approach that everyone really wants to mainstream into the normal community. I sincerely doubt that this is true.

13. The assumption that independent apartments is the best way to go or that it is the normal process for independent living flies in the face of developmental theory. As is known, many persons with severe and persistent mental illness have their normal developmental processes interrupted by hospitalization or by symptom development. Many need to go through these stages in some modified form and at their own pace. Group living can offer this opportunity.

Poorly run residential programs of whatever style will have serious weaknesses and are a danger to both the member's self-esteem, safety, and future growth. The answer lies not in completely rejecting any particular model, because when well executed, each has significant strengths, and can be natural and completely supportive.

There definitely are drawbacks to group living for some people, and it is also wise that we must continue to keep in mind our members' wishes; however, it is also true that many people have found great comfort, solace, and growth in group homes and, indeed, have made the transfer of training necessary to become independent and have enjoyed their experiences. Different strokes for different folks might well be our motto.

Having discussed the "one style" approach, let's get on with solving problems. In my experience with housing, there are four persistently difficult issues. They are:

- capital funding,
- operational funding,
- stigma of mental illness,
- zoning.

Capital Funding

This is a chronic problem, one that at times appears almost insoluble. There are a few sources for capital funding. Currently, the one that is being promoted is the Department of Housing and Urban Development (HUD). Since I have had some experience with this agency, I feel confident to say that they are definitely not the right governmental agency to work on this problem. Our agency has had three HUD projects, all successful, all enormously time-consuming (up to five years, in some cases), and all beset by an incomprehensible maze of burcaucratic regulations that defy any mere mortal from attempting this route. Of course, our agency has hired a consultant, which is all to the good, but our goal is to make housing *easily* available and to *encourage* agencies to develop housing. The difficulty of the HUD process is so manifest, their rules so arcane, their understanding of mental illness so prehistoric, that their control of the funds that are needed is, to put it mildly, a grave mistake. HUD rigidity is legendary. For instance, in developing housing for psychiatric patients under a studio apartment building concept, it is necessary to have some common area where members can get together and socialize and to put in an extra kitchen in that area so that members can have meals in common once or twice a week. This simply can't be done with HUD.

My suggestion would be to have HUD get an allocation of housing dollars from Congress and transfer the money to the National Institute of Mental Health and from them through the Block Grant program to states. This will permit those who are closer to the scene and more in touch with a common sense approach to housing to really take charge. The state itself should not develop the housing but would, in turn, grant and/or loan money to community agencies to do that. In addition, I think that NIMH or HUD should sponsor a contest for architects to develop a series of basic designs which could be used by any agency who could add their own variation. We don't need to take a cookie cutter approach to this but neither should we invent the wheel again. Having this competition might engage HUD in the possibility that there is another way to do things. In addition, construction under HUD standards, is too expensive and their regulations tempt you to spend money on things that are not necessary and forbid you to spend money on things that are necessary.

Another approach is to have states themselves use their power of eminent domain to acquire property or land, and then completely develop it, so that the facility could be leased to agencies for the ongoing operation of a project.

Regulatory flexibility is most important and much work needs to be done with regard to the building codes. Prefabricated buildings should be used more frequently. Parking regulations should be waived. The city could write down the cost of land and other archaic building codes should be waived.

The use of tax-exempt bonds could become a major inducement to promote the availability of capital. Each state has a Housing Development Authority which usually has the power, but not the will to utilize their bond capability to provide acquisition and renovation funds. These bonds should be guaranteed by the states themselves so that the buyer of the bond could not only be secure in the repayment of the bond but also gain benefit through a tax-exempt status.

It is possible, and a good idea, with architectural innovation and creativity, to build SROs and other housing stock in small rooms no bigger than 250 square feet, with congregate eating and shared bathroom facilities.

Can we entice private developers to provide funds for capital and to do the contracting? "Yes", if there were some inducement for them to do it. Obviously, it can't be the rents of our clients since Supplemental Security Insurance (SSI) and Social Security Disability Insurance (SSDI) provide only the very basics and those on Public Assistance only have an even lower level of living. So, there needs to be some definite commitment to an operating subsidy for debt service and modest

profit for developers. My suggestion again would be the Departments of Mental Health of individual states.

The point is, there are methods either in existence, or opportunities that could be modified to make them more usable, or we need to invent new ways to provide capital. It can be done if it gets the right amount of intelligent attention.

Operational Funding

While it is clear that all four of the problems mentioned above need to be addressed, if there is no good source for operational funding, the whole idea of housing collapses. By operational funding, I mean the actual cost of running the housing: heat, light, etc., staffing costs and debt service.

Since I believe that housing is the highest priority, I, therefore, believe that state and county funding sources should give it their highest attention. One way to do this in states or counties where agencies are reluctant to start housing, is to tie other program grants to residential operational grants. In other words, make some other grant contingent upon providing housing.

As mentioned earlier, debt service is critical since bonding agencies, either private or public, will look to the commitment of the state or county to provide debt services as an ultimate criteria for their issuing bonds.

With regard to staffing patterns, the funding agency has to be sure about what level of clientele is being housed as the prime criteria to providing differential staffing patterns. In some housing situations where there are clientele who are at greatest risk for re-hospitalization, you will want to provide the highest degree of staffing pattern. That means shift staff who are awake and on duty 24 hours a day, seven days a week.

In housing for crisis and emergencies, with members who abuse substances, for older adolescent populations, and for other special groups, such as the deaf/mentally ill, this is a necessity. A lesser level of staffing is to have a staff member "live in" but not be awake 24 hours. Their mere presence provides a calming influence as well as someone who can deal with emergencies, even in the middle of the night, when they arise.

A still lesser level would provide for staff being on duty, up to around 10 p.m. and then they go home.

A lesser level yet would be staff members who periodically visit the house to provide some sort of supervision, training or treatment.

Yet, it is more than staff "coverage" that is important. In some systems a differentiation is made between this level and social work treatment level. In my judgment, both are valuable. House managers handle the day-to-day activities and the management of the house, and the social worker handles the treatment aspects. Naturally these varying levels of staff have a direct impact on the operations support needed.

The Stigma of Mental Illness

The third problem is that of **stigma and community opposition.** This issue, while not always insurmountable, is troublesome. The stigma of having unfriendly neighbors who are known to be psychiatric patients is a problem that has plagued many of us in the field. The fact that the community has no control over any other of our neighbors appears to be almost irrelevant to this group. A child molester, rapist, or other criminal could buy the house next door and no one could do anything about it, but when a psychiatric patient moves next door, there is too frequently a concerted pattern of opposition.

NIMH should take a major role in combating stigma and to a certain extent they already do so, but this agency needs to be more powerful and influential within print and TV media particularly in presenting cases where stigma has been diminished on the basis of community experience. This has occurred in a number of communities and NIMH has actually produced some documentaries of this type. Much more of it needs to be done. In addition, the National Mental Health Association should be an important player in combating stigma. This is the reason they were formed in the first place all those decades ago. This item should be close to the top of their agenda. Perhaps a national committee should be formed to combat stigma regarding psychiatric patients with special emphasis on housing. Hopefully, some top flight advertising personnel, as well as celebrities might be included in this committee.

States and counties need to get on the side of agencies in an **active** way so that an individual agency can feel that their Department of Mental Health is actively on their side and will fight right along side them when issues of community opposition and stigma come up. On a practical level, this means that the states must develop public relations materials and prepare themselves to be active in local disputes. Too often state Departments of Mental Health have left agencies to hang in the wind when there is a stigma situation. It should enter into the fray as a friend of the court and be willing to sue on behalf of this issue.

One additional factor in the mitigation of stigma involves the words for the illness that we are dealing with. "Schizophrenia" carries with it an extremely negative connotation, one that tends to strike fear into the hearts and minds of the public. A change of name of the illness would be welcome. I do not make this suggestion lightly as "schizophrenia" has a long history. The concepts underlying schizophrenia, as well as newly discovered etiology, have made significant changes over the years and a name change would help. Lest anyone think this name change is merely cosmetic, let me remind them of the past fear in the mental retardation field. When I was young people with mental retardation were termed either an "idiot", "imbecile", or "moron", depending upon their IQ levels. These words obviously reached into the lexicon of the general public, creating a negative connotation. It has only been in my professional lifetime that Down's Syndrome has come into use. Think of the difference between "idiot" and "Down's Syndrome" and you may have some idea what a name change might bring to those afflicted with severe mental illness. My suggestion for this name change would be "neuro-transmitter/stress syndrome". Although the complete etiology of schizophrenia still escapes us, enough is known about the dopamine hypothesis to support the term "neuro-transmitter/stress syndrome". Other suggestions, of course, would be welcome. The name change might also be accompanied by some descriptive statement regarding the severity or duration of the illness, such as mild or episodic or persistent. The key point is that "schizophrenia" itself as a word has so much

negativity tied in with it that it actually creates the stigma that we would like to eliminate. Also, to be eliminated should be the terms "mental illness" that describes very little and obscures the difference between intellectual level, emotional functioning, and a host of other issues that tend to cloud that term.

Zoning

The fourth problem is that of zoning. To a certain extent, this is related to stigma, but it is not the same. When community members and politicians want to stop housing development for psychiatric patients, they frequently use zoning laws to do so. Groups of psychiatric patients are not allowed to gather together in compatible housing environments because zoning laws are stacked against them. Many of us have been through the zoning wars with little or no success. Occasionally, an agency can manage to fight their way through a zoning law barrier, but most of the time it doesn't work.

This is particularly acute in the area of group homes, the one style of housing which I consider to be particularly important and worthwhile. The whole problem is akin to the civil rights laws in the sixties. Before civil rights laws, it was legal not to serve black people at counters and to enact special voting laws which discriminated against them. Then the civil rights laws were passed by Congress, which preempted the states' abilities to allow discrimination. After the laws were passed, it turned out that people were willing to obey the law, whatever that law is. And although some turmoil continues to exist, the basic civil rights and anti-discrimination laws have been working to a remarkably successful degree.

The situation is similar with regards to housing for psychiatric patients. I would suggest that the anti-discrimination statue be changed so that it includes the words "disabled" under those categories of people who can't be discriminated against in housing. There might be other ways to handle this through a different law, but it definitely needs to be done on a federal basis rather than on a state-by-state basis. It should be against the law to discriminate in the provision of housing to psychiatric patients through the use of restrictive zoning statutes. It is crucial that psychiatric patients get their rights back in this area.

The Role of Parents

Much has been written about the role of parents with regards to their mentally ill children. I would like to approach this issue from the point of view of independent living and its meaning. The prevailing notion within the field is that parents need to be helped in learning how to better handle their child at home and this is sometimes expressed in parent education classes or psycho-education, as it is called. The other serious effort is to help the parents to eliminate their highly expressed emotions, the so-called EE concept. I disagree with both of these two ideas. I think the most important attitude a parent can have is to encourage their child to leave their home. All this is predicated on the availability of housing, naturally, but this is still an issue regarding the attitude of some parents. One way to counter this attitude is with a parent support group. At our agency, Thresholds, we give the consistent message that the greatest love parents can show their child is to allow and encourage the child to separate from the parental home. Some studies have shown that self-esteem is lowest when living at home. Those parents who still feel that maintaining the child in the home for "as long as the child needs us" is the primary criterion of their good parenting, are often shocked by our advice. We usually explore the process of the child's emancipation as a loving, positive act, rather than a rejection. Their child's growing maturity and independent future are overriding concerns. The greatest gift of loving concern is their insistence that the child become independent, provided, of course that there are facilities to accept them.

Naturally, parents must face the question of their own mortality and must ask how they are preparing their child to live without them when they die? This is faced directly in our parent Support Group and expressed bluntly during group sessions.

We view the trend to educate parents in the best ways of managing their children at home as not a positive direction, and their energies might better be spent in advocacy efforts in getting housing services of any effective style that are so desperately needed.

Homelessness

Clearly, homelessness is a special problem of the mentally ill. Estimates of the number of homeless are usually centered around the one-third level, so if there are 12,000 people who are homeless in any city, as there are in Chicago, we estimate that 4,000 of these will be former psychiatric patients who, as a direct result of their mental illness, are homeless. There are many reasons for this and some have been documented in the literature. Crucial among them are the virtual elimination of single room occupancy hotels (SRO) and other opportunities for modest rental housing. It is to this issue that we need to raise our attention, but we won't get anywhere with this problem unless and until professional discharge plans are made at the exit of the hospital. It needs to be mandated that every person leaving a mental hospital have a really effective workable housing plan as part of their total discharge plan.

Whether state staff officially acknowledge it or not, it is often the practice to discharge people with psychiatric disabilities with a phony address or even directly to the Mission or to shelters. This is not, obviously, a decent approach and large scale housing needs to be implemented to counter this anti-therapeutic trend. In my district some serious consideration is being given to instituting an ambulatory commitment for those people whose history indicates that they do not handle themselves in the community in any responsible way in regards to housing or self care.

Yet, we must be vigilant in even considering this idea, that the civil rights of these people be protected. I wonder if it really is a civil right to be homeless if you want to, particularly if you are operating at a level where your mental processes are not rational.

Housing alone, however, is not the complete solution It must be accompanied with assertive programs of outreach to those who are homeless and, as indicated, high level and professional discharge planning. It needs to become the business of hospitals to be sure that they are not discharging people to the street.

Summary

Issues of housing are genuinely complex. There is much to be said on all sides of every single issue, except that the need is there. About that there can be no dispute. The approach of this paper is to outline several principles.

Foremost among them is that a **wide variety of housing opportunities is the best way to approach the topic, not a single level approach.**

Second, **capital funding** requires an assertive response and sophisticated investigation. Much more needs to be done by state and federal governments in providing new ways to provide capital funding.

Third, **operational funding** needs to be guaranteed, either by state or county mental health authorities, and this needs to become a highest level priority in their system.

Fourth, the **stigma** surrounding mental illness needs to be addressed directly and it might well include renaming the illness that we are dealing with.

Fifth, **zoning** is a severe impediment to housing and needs to be addressed through legislative action.

Sixth, **parents** are the greatest ally that we can have. They need to orient their own efforts, not so much to providing a comfortable place in their own home for their child, but rather toward encouraging and indeed insisting that their child become independent, provided, of course, that decent housing and supervision is available.

Seventh, **homelessness,** a special issue in the housing arena, is a difficult one to deal with, but can be addressed through good discharge planning, the possible provision of ambulatory commitment, assertive outreach, and most of all, affordable housing.

Joan Barker, Paul Carling, Jacquelyn Dickerson, and Ralph Fasano (l to r)

(l to r) Christy Disher, Dr. & Mrs. Larry Scadden, Esso Leete (front) and Robert Neuman

Scenes from the Seminar

Jerry Dincin and Laurie Flynn

John Sheets, Ralph Fasano & Jacqueline Parrish (l to r)

Excerpts of Reviews & Comments

The following are excerpts of reviews, comments and recommendations made by the 1988 Switzer Scholars. These are presented to further stimulate thinking, discussion and action as they relate to the content of "Housing: A Crucial Dimension" by Jerry Dincin, Ph.D.

I certainly agree with Dr. Dincin that housing is a crucial element of rehabilitation services to the seriously mentally ill.

His emphasis upon group living arrangements as part of a spectrum of types of housing is well put. Even though the emphasis on group housing may seem at variance with his plea for an array of choices, it does seem necessary in the face of the current popularity of "scatter housing" (units for one, two or three clients each). However, the types of housing actually available in a locality are most often dependent upon factors over which the rehabilitation and mental health systems have no control, and group homes may not be an option in many locales. The costs of acquisition, remodeling or construction, and the opposition of residents in the area often rule out options other than small physically discrete units.

I, too, believe that an array of housing choice is best, for all the reasons Dincin ably enunciates. Group living should be a choice for many psychologically fragile people, but even where it cannot be managed many of the desirable elements Dincin enumerates can be fabricated, at least in part, with other housing arrangements. I have seen group cohesiveness, sharing, and support among clients living in scattered housing through imaginative use of staff and programming. It is the totality of life space, the independence of the living arrangements, the closeness to normalcy of living that is significant--not necessarily the congregate nature of the architecture.

One issue that Dincin only alludes to, but which I believe can become a serious complication for those planning residential rehabilitation services, is the attempt by mental health authorities to insist upon a sequence of housing purporting to meet functional diagnostic needs of clients as determined by clinical measures. New York State, for example, has set up a series of approved housing, from intensive supervised to supervised to various gradations of supportive housing intended to operate in a "step system" as the client becomes progressively more functionally capable. To a rehabilitation professional such a program is anti-rehabilitative if not downright silly.

I am intrigued by Dincin's advice to parents that they "let their children go." This is admirable advice. I wish the mental health and rehabilitation systems gave greater assurance that this is justified.

-Bertram J. Black

A more extensive paper, "Housing and Support for People with Psychiatric Disabilities: Directions for the 1990s", which I have authored is included elsewhere in this Switzer Monograph. It summarizes the dramatic changes in thinking which the field of mental health is struggling with, including taking responsibility for an appropriate role in housing, expanding relevant services to people with psychiatric disabilities and their families regardless of where they live, and working within the constraints and opportunities represented by consumers' own choices. In this process of re-evaluation, there has been significant learning about the uses and limitations of current program approaches, a much more sophisticated understanding about what it takes to make "independent living" work, and most importantly, the beginnings of information about where and how consumers want to live. In the increasingly voluntary mental health system of the future, such information is critical

These separate comments here address in more detail many of the issues raised in Dr. Dincin's paper, which contains a number of valuable insights about serving people with psychiatric disabilities. These include the observation that people with major mental illnesses are very varied in their characteristics and their needs, that a variety of options ought to be available to people, the fact that people need social support, and that peer support is particularly helpful. Unfortunately, he appears to assume that all of these insights should lead to a conclusion that the preferred living arrangement for people with psychiatric disabilities should be a segregated group home.

Dr. Dincin's paper begins with a strong and appropriate call for mental health agencies to make housing "their business," a call which is necessary and long overdue. Unfortunately, the major section of the paper goes on to create an unnamed "straw man," described as the "correct style (of housing) as some writers have indicated," and then to point out the apparent weaknesses in this point of view. Although I am fairly familiar with the literature in this area, I do not recognize the work that Dr. Dincin is describing. It would have been far more helpful if Dr. Dincin had included specific references to this point of view, or in fact, references to any of the substantial and growing research and practice literature in this area. Having constructed this "straw man," Dr. Dincin then goes on to describe this point of view as opposing group homes, and proposing that everyone should live in an apartment. And while Dr. Dincin acknowledges the "advantages to a scattered site long-term housing approach," he goes on to suggest that most "members" **need** a "nurturant living situation that is best exemplified in a group home."

In fact, one of the most difficult dilemmas the field appears to be facing today concerns the issue of "**need** according to whom?" We are aware, as I point out in my paper, that there are profound, and apparently consistent differences of opinion between service providers and consumers about what kinds of housing and supports are needed. In the scarce data that is available, including Dr. Dincin's observation about members in this paper, the

great majority of consumers express the same housing desires as the rest of us: regular housing, typically with a roommate, and ranging from apartments to a single room to a house. Home ownership appears to be a strong interest when the finances and supports to make that a successful arrangement are available. Some small proportion of consumers express a preference for small group living (without staff) in much the same way that some small proportion of the overall population in any community would opt for this arrangement.

So the real issues we are left with are whether we take these preferences seriously and how to incorporate consumers' choices into our services. Switzer Scholars Dr. William A. Anthony, Esso Leete and Dr. Agnes Hatfield all speak to the critical importance of consumer choice as the essential element of an empowering rehabilitation approach.

Dr. Dincin defends his position that people should live in group homes by pointing out that "although it is theoretically desirable for people with persistent mental illness to integrate their social lives with their neighbors, this is an almost completely unrealistic expectation." But as Dr. Hatfield points out in her paper, "The Role of the Family in the Rehabilitation Process", many consumers are doing just that, with the support of their families. And there is an abundant enough literature in social psychology on the powerful effect of expectations to lead us to conclude that, if our expectation is that people cannot be successfully integrated, we will do little to accomplish this goal, and both consumers and the public who observe our programs will also come to believe this "truth." The tragedy is how we have allowed such "truths" to limit the lives of **individuals,** in spite of our knowledge that it is virtually impossible to predict the outcome (See Dr. Anthony's extensive work in this area), and that for people with major mental illness **in general,** outcomes are surprisingly positive over the long term (See Harding and Brook's work).

Fundamentally, like much of the early work on residential services, this paper fails to address **housing issues,** and by not making a clear, but essential, distinction between housing and services, it mostly talks about **residential programs,** and even seems to suggest that we must **change** between housing and residential programs for people--an absurd and impossible choice. Housing and treatment are, for the most part, separate issues. But, as one reads this paper, the author seems to assume that most or all consumers will live in "programs." The paper, for example, is quite unclear as to what terms like "scattered site long-term housing" or even "group home" mean. In fact these terms are used across the country to describe widely different approaches. In Dr. Dincin's paper they appear to suggest different program models. But in fact, some of the most innovative thinking in mental health systems today, summarized in my paper, reflects a growing awareness that only a very small percentage of consumers in any system (two to five percent) live in residential programs, and given the cost of such programs it is unlikely that significantly more will do so. Further, there is growing dissatisfaction among consumers about only having residential programs as a housing option. In fact, the overwhelming majority of consumers do live, and prefer to live, outside of programs. This is not to say that residential programs are not necessary. It is to say, however, that our major challenge becomes how to help people select and maintain decent, stable housing and then to support people regardless of where they live.

We are also coming to understand that the concept of independent living itself is fraught with problems. In fact, this is another "straw man" presented in this paper, i.e. the notion of consumers living on their own without supports as some kind of unrealistic ideal which "some writers" are advocating. While it is appropriate to have as a goal reducing the individual's dependence on formal systems of services over time, the reality is that no one lives independently. Although Dr. Dincin denigrates the importance of skills training, the literature and practice suggest it is a critical element of a rehabilitation approach, and needs to be available in a variety of ways, including to people in their own housing, regardless of where that is. The reality is that we all need skills, and we all need a flexible and long-term network of relationships and supports to be successful. So the field is starting to redefine the concept of independent living to include these supports to individuals and their families, and to consider the use of peer support in the process.

Perhaps the most telling criticism of some of the ideas expressed in this paper is the fact that the leadership of most organizations in mental health are increasingly focused on the need for decent, stable and affordable housing, on the need to respect and support consumers' choices related to housing, and on the need to offer flexible and long-term supports to individuals and their families regardless of where they live. This emphasis on housing is apparent regardless of one's vision of the relative worth of a particular treatment approach, including residential treatment. This focus is clearly reflected in the policy positions of the National Association of State Mental Health Program Directors, that of the National Institute of Mental Health and the National Institute on Disability and Rehabilitation Research, and the state Community Support Program Directors. These approaches were included in a consensus testimony before the United States Senate committee which is redrafting federal housing legislation.

Perhaps most problematic in Dr. Dincin's paper is the absence of recommendations for the future which would address the day to day problems that consumers, their families, service providers and advocates face as they try to help people select and stay in decent, stable housing, and to organize the supports people will need to achieve this goal. We are coming to understand that these problems are due as much to such factors as poverty and discrimination, and the loss of affordable housing, as they are to any of the limitations which a psychiatric disability imposes on an individual. Fortunately, mental health systems at state and local levels, along with advocacy groups, are developing strategies and solutions that go far

beyond a call for more capital funding for residential programs, or strategies to "force" communities to accept more group homes through zoning changes. Instead we are seeing systems begin to consider basic improvements in consumers' income, expanding the number and type of housing options available to consumers, a stronger emphasis on the development of new housing in which consumers can occupy some of the units along with other community members, on ownership options, and on expanded supports to consumers and their families including case management, crisis services, and peer support. While a small number of increasingly specialized residential programs will continue to evolve, for the vast majority of consumers in the mental health system of the future, expanded support in their own housing will clearly be the preferred approach.

-Paul J. Carling

Experts seem to agree that what is needed is a broad spectrum of housing. At one extreme a staff person would be awake around the clock; at the other extreme there would only be a counselor available by phone or visits in case a problem arose that could not be handled. In between these extremes should be board and care homes, foster care and scattered apartments with visits by providers. A very important part of this spectrum is the need to develop consumer-run alternative housing programs. The needs of the homeless mentally ill could also be met by consumer-run housing and outreach services. In Philadelphia, there is both. One is called OATS--Outreach, Advocacy and Training Services--where former homeless mentally ill people help others currently on the street hook up with needed services. Homeless people would be more responsive to people who have "been there." The federal legislation to help the homeless, entitled the Stuart B. McKinney Act, makes funds available to consumers to provide services to homeless people. The problem is that the provisions of this Act and means of accessing the funding is complicated to try to navigate. One way of trying consumer-run housing is to have an expatient whose illness is under contr[illegible] be "friends" with the patient and make daily visits to their home and help them with basic needs or even help them access services like Social Security. (As an aside, it needs to be mentioned that the current Social Security Administration is befuddled with so many problems that it makes overpayments as well as withholds checks. It is a monster to negotiate. Action is needed to change the way it is run and managed. Social Security does not understand the nature of mental illness and the working needs of the mentally ill.)

One method that could be used to help the housing situation is "single stream" funding. This is where money flows from the state directly to the county or planning agent and then is awarded by contracts to provider agencies. This would solve the problem of confusion and lack of coordination between states and counties and providers in regards to housing.

-Christy Disher

The recognition of housing as a vital component of any rehabilitation program for people with mental illness is an important one. Why it has taken us so long to recognize this obvious truth is beyond any logical frame of thinking. People with mental illness, as with all people, cannot function without safe, adequate housing. When individuals are institutionalized the hospital becomes their home. Basic needs such as food, clothing and shelter are provided by the hospital. Upon being deinstitutionalized it is imperative that a plan be developed for filling these needs in the community. Referral to a community mental health center that provides treatment and opportunities for rehabilitation, while important, is not sufficient to help individuals remain in the community. The author makes a point that CMHC's must attend to the housing needs of their clients. Hospitals must have adequate housing plans before discharging patients. However, these goals are made difficult to attain due to the shortage of appropriate housing for our clients. The author's analysis of several key problems which obstruct the development of more housing for this population, namely, capital funding, operational funding, the stigma of mental illness, and zoning, lead to several policy implications. I am in wholehearted agreement that there needs to be less cumbersome programs for capital funding than the ones that currently exist. The potential five year development time to create a HUD 202 program is unacceptable, given the immediate needs for housing. However, when joined with state capital and operational dollars, as is done in New York State, these programs have the potential of being model residences for the mentally ill. The author's suggestion that these dollars be turned over to agencies more experienced at providing housing for the mentally ill is a good one which deserves further discussion. In New York State, it would certainly decrease some of the bureaucracy if the State Office of Mental Health controlled these dollars.

The author's point that there is no one effective independent living program which should be developed at the exclusion of other models is an important one. Different people have different needs, and policies that stifle an agency's creative attempts to meet these needs are a hindrance to progress in this area. Flexible policies are essential. On the other hand, agencies should be accountable for the programs that they develop. Research on such topics as what type of setting is best for what type of resident is essential.

The concept of creating permanent housing for the mentally ill must be addressed. Most of the programs that currently exist are transitional in nature. Yet the nature of the diseases that we are helping people to cope with are often lifelong illnesses which may prevent individuals from moving through our continuum of services. The author's suggestion that we develop a wide array of housing alternatives as opposed to a narrow focus on transitional programs is important. Included in this array must be the provision of permanent housing for those who need it. Research aimed at quantifying how

many people need the various different levels of supervision described in this paper would help us plan for the type of programs we need to develop.

The author's statement that independent living opportunities "can offer the single best opportunity for personal growth for our members" is one that should be more fully recognized in the field of mental health. Community residence workers are often grossly underpaid and undervalued as mental health workers. Their work is often looked upon as being unimportant, as compared with "treatment staff" at clinics. Their opinions and feedback to other professionals is often ignored. Yet it is these individuals that spend the most time with clients and attend to the most important needs that they have. Having worked in both clinic and residential settings, my own experience validates the author's impression that a good independent living program can be our best tool for developing human potential. Yet the oral problems of low pay and poor image create high staff turnovers in these settings. Lobbying efforts must focus on rectifying this situation.

-Ralph Fasano

Housing is a crucial dimension of psychiatric rehabilitation and recovery, even basic survival, for people with mental illness. It does need to be available on a wide spectrum, and there must be flexibility. I personally believe that the vast majority of mental health clients do want to live independently, in their own apartments, although many realize this cannot happen immediately. However, congregate facilities are scarce in every neighborhood. Zoning restrictions must be amended, especially as they relate to community group homes, and we must establish federal laws so that all people with disabilities, including those with mental illness, cannot be discriminated against in housing or in any other aspect of their lives.

Taking into account as a top priority the clients' wishes, we must design programs to ensure that a variety of residences are available to consumers. First, bureaucratic regulations should be simplified. Block grants could provide housing units through the states or states might acquire property through eminent domain. Private developers must be approached and creative financial incentives established to entice their involvement. A good idea, and one which I believe has been successfully attempted, is to make other grants contingent upon providing this housing.

Stigma continues to act as a barrier, preventing mental health clients from residing where they wish in the community. All mental health related organizations must work diligently to combat this stigma, as must individuals suffering from mental illness. We must transform current societal stereotypes by our accomplishments and our lives. Perhaps a name change for "schizophrenia" and "mental illness" would be instrumental in decreasing stigma, but it may be that no matter what you call such a disabling and catastrophic illness, it will be stigmatizing to those carrying the label.

-Esso Leete

It is hard to add anything to this comprehensive, knowledgeable and caring paper. Dincin knows the psychiatrically disabled population very well, and his ideas about housing alternatives and community integration are based strictly on the realities of multi-modal needs, capabilities, and limitations. His insistence on a range of housing options, and his knowledgeable distinction between the concepts of "continuum" and "array" are theoretically as well as practially important. There is a refreshing recognition that if we are to speak about legitimate alternatives to hosptialization, community housing must serve the least as well as the most functional, including those not likely to move in accordance with our plans.

I completely agree with the paper's criticism of the current emphasis on scattered site separate apartments. It seems illogical and countertherapeutic to promote a sense of community and belongingness in the clubhouse model, and then erode it in the housing model. As Dincin indicates, programs must draw a fine line between attending to pragmatic financial and zoning issues and developing the most therapeutic residential arrangement. Too frequently in mental health planning, cost-efficiency takes primacy over cost-effectiveness; we forget that the bottom line is what is ultimately best for the consumer.

Dincin's emphasis on group settings and communal living is critically important. As he points out, this arrangement counteracts loneliness. It encourages growth in a companionate setting by providing friends and peer support. By offering opportunities for interdependence, it cuts down on dependence on professionals. Dincin says other important things that need saying, counteracting some myths in the field about mainstreaming and full community integration of psychiatrically disabled persons. In the discussion of homelessness, his point about hospitals discharging only to a known address is critical. It recognizes that deinstitutionalization cannot be considered a reality, or even a desideratum, if there isn't a community bed in which the patient can sleep.

Dincin's suggestions on developing capital and operational funding are excellent. His ideas on the transfer of HUD allocations; on the states using their power of eminent domain to acquire property and issue tax-exempt bonds; on architectural design contests; and on enlisting state Departments of Mental Health for incentives to developers, are all feasible, if there is an appropriate constituency lobbying federal and state legislatures. In fact, his suggestion that the non-discrimination statute be changed to include the generic term "disabled" is currently under consideration as a case in point.

This brings us to the only weak part of an otherwise fine paper: the comments on parents. Dincin's use of his agency's parent support group as his source of data, and limiting the discussion to the problem of convincing parents to encourage independent living, is extremely puzzling. Research indicates that most parents do not want to keep their disabled adult children at

home (Lefley, 1987). They maintain them not because of guilt or illusions of good parenting, but primarily because acceptable housing alternatives are not available. The section on parents should be focused on enlisting parents as advocates and lobbyists to promote the excellent ideas Dincin has presented for legislative action. The best recommendation to link parents with an advocacy group, such as National Alliance for the Mentally Ill (NAMI), so that they may go beyond verbalization to join a constituency with the potential for political influence. This is really the only way to implement the options for independent living that everyone desires.

References

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-Harriet P. Lefley

I very much agree with Dincin's comment that "to strongly emphasize one style of housing and denigrate others as the wrong approach, seems to be a false step. . . ." Yet, Dincin appears to be arguing strongly for group homes. His paper also points to the paucity of research results which we have as regards to residential treatment. For example, he does not offer documentation to support the statement, "Rehabilitation can occur and does occur in all of the styles [of housing] mentioned." I would agree that steps toward rehabilitation may occur, for example, in a boarding home, but, in the absence of research data, I am not sure that the process can be completed in such a setting.

Dincin argues that "communal living. . . may be frequently expressed in our culture in the style of a fraternity or college co-op"; he failed to mention that this style of living lasts, for most folks, only four years--and certainly not a lifetime.

I am not at all sure that research, or clinical experience, indicates that special populations such as persons who are deaf and who also have psychiatric disabilities need housing where "shift staff . . . are awake and on duty 24 hours a day, seven days a week." While this population may have special needs, is over protection really one of them? Can their isolation really be remedied by having them live together? In a 1987 survey of partial hospitalization programs in Colorado, it was found that of 33 programs, only six (6) or 18 percent employed staff that knew American Sign Language. Perhaps this is where we begin. . . .

Catherine A. Marshall

Housing is indeed crucial. The issues mentioned combine to make this a most formidable task. Reality tells me that what we like and what we get will be two different things.

Ideally, a spectrum of housing is what is needed. Realistically, the cost of obtaining and maintaining that array of housing is not possible at this time. Federal, state, and county fiscal conservatism make adequate housing difficult. Recent rehabilitation legislation established and maintained Independent Living Centers (ILC's). That appears to be a vehicle that can be used. Each state functions differently making uniformity difficult.

A major concern in helping any person function independently is getting the person to act responsibly. Although all people have rights, those rights are taken away if one doesn't act responsibly. Convicted felons and poor driving records are examples. To maintain rights, one must act in a responsible fashion. As rehabilitation professionals, our responsibility is to work with all clients; to jointly develop a rehabilitation plan tailor-made to meet the needs of that client. The end result gives that person an opportunity to enter or re-enter the work force. Responsible workers are what the nation's employers are looking for. Helping all clients attain this level is our job. In dealing with the psychiatrically disabled, the first major step in the rehabilitation process is a good housing situation.

-Robert J. Neuman

The author makes the case that within psychiatric rehabilitation an array of housing services should be made available. He states that it is an error to rely upon the assumption that separate scattered site apartments are better than other styles of housing. He prefers numerous housing options that are flexible, and he presents his rationale. In addition, he discusses four persistent problematical areas in housing: captial funding, operational funding, stigma and community opposition, and zoning.

The author is on target when he argues for a wide variety of housing options. The right of every citizen of this nation is the right to alternative choices. Just because a particular housing service is promulgated, its existence does not mandate that it becomes the recommendation of choice for all mentally ill persons requiring housing services. A big issue within special populations is the right to alternative choices. For example, if a special program is specifically implemented for a particular group such as deaf persons or blind persons, it does not mean that those persons are limited to those programs. They have the right to go where they wish for services, so too, with mentally ill persons.

Stigmatization of mental illness and community opposition has become the backbreaker for mental health community service providers. In regards to housing, providers rather than responding to the actual housing needs of mentally ill persons, may be choosing to establish particular programs such as scattered site apartments and independent group homes because they do not want to confront community opposition and zoning problems. Providers frequently stand alone with no support form city administrators and politicians. Simply said, it is easier to take the path of least resistance.

Hopefully, the family and consumer movements that are continuing to grow will one day impact upon city administrators and legislators to establish strong zoning and anti-discrimination regulations and laws to give people with mental illness the right to fair and equal housing as well as other program services. This movement would be

parallel to that for mentally retarded and developmentally disabled persons in the past 25 years. Only with such laws and regulations will discrimination and stigmatization be reversed.

Too frequently, within the area of mental illness, we see the effects of negative media and print coverage. The question needs to be asked, "has there every been a successful public relations campaign directed at correcting the stigma of mental illness?" If so, what was it, and what were the results? NIMH needs the resources equal to the level of the current campaign on AIDS to comprehensively address the stigma of mental illness. Strategies also need to be developed and carried out in combating news media bias. Sensitization and education of TV and radio program directors and news reporters are needed.

-Carole Schauer

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Summary of Recommendations on Housing

The following is a summary of recommendations for action developed by the 1988 Switzer Scholars as they relate to "Housing and Support for People with Psychiatric Disabilities: Directions for the 1990s" by Paul J. Carling and "Housing: A Crucial Dimension" by Jerry Dincin.

I. Major Recommendations

A potent, convincing national campaign is needed to counter the unsubstantiated and injurious assumptions the general public has about the abilities and potentials of people with psychiatric disabilities to live, learn and work in local communities. People have a **Right to Recovery**. This campaign should involve the National Institute on Mental Health (NIMH), the National Institute on Disability and Rehabilitation Research (NIDRR), Rehabilitation Services Administration (RSA), National Alliance for the Mentally Ill (NAMI), consumer groups, provider and advocacy organizations. The major focus of the campaign should be on promoting equal opportunity for full participation in the community.

II. Service Delivery Recommendations

1. All mental health systems (federal, state and local) need to recognize that decent housing is a key need of all people with psychiatric disabilities, and that they have lead responsibility for facilitating and advocating that these needs are met.

2. Mental health systems need to view housing as integrally connected with community support systems, including supports for people who are homeless. Supports are needed for consumers, families, landlords and significant participants in the process of helping people succeed in housing.

3. Mental health systems need to engage and deal with the importance of consumer choice related to all aspects of housing and supports. Consumer choice needs to be an essential element of all programs and services.

4. Mental health systems should encourage consumers to be hired as paid staff in housing and support programs.

5. Mental health systems have a responsibility to assure that rehabilitation services are routinely available to all consumers regardless of where they live. Programs and services need to become much more consumer-oriented and oriented to clear outcomes related to housing.

III. Policy and Program Development Recommendations

General:

1. The prevention of homelessness is a major goal and is achievable. A key need is for a much closer working relationship between community and hospital staff around discharge planning, so that people routinely have housing available when they leave the hospital. Also needed are much stronger efforts to help people hold onto their housing while they are in crisis or in the hospital.

2. State mental health departments need to hire technical experts in housing finance and development, to provide technical assistance to local areas and to "broker" collaborative projects with mental health and public and private housing groups.

Housing Development:

1. As housing is accessed or developed, mental health systems must guarantee that there will be resources to support people in that housing, and also make arrangements to assure that the operational costs of the housing will be covered.

2. Local housing development corporations should be expanded and existing ones focused on working with the housing needs of people with psychiatric disabilities.

3. Mental health and housing systems need to work together to arrange for rehabilitating currently abandoned buildings to provide both housing and work opportunities for consumers.

Consumer Issues:

1. State and local mental health systems need to develop strategies to increase consumers' income so they can access decent housing. A major effort should be directed to developing rent subsidies similar to Section 8, at the state level.

2. Mental health systems should support innovative efforts of consumers to meet their own housing needs, including consumer-run housing services.

Services:

1. Mental health systems need to provide flexible supports to people regardless of where they live. They also need to make services available on a long-term basis.

2. A rehabilitation approach to housing needs to be mandated throughout mental health systems.

3. In order to support people in their housing, systems need to give a much higher priority to substance abuse issues and service needs.

4. Mental health systems need to promote higher status and salaries for staff working in the area of housing and supports.

5. In order to increase innovation, local providers should be given a high level of flexibility in developing solutions to the need for stable housing and supports.

6. In approaching the issue of how many consumers might live in a particular housing situation, providers should understand that this is principally a matter of choice, and that in any case, the standard should focus on what is common for people without psychiatric disabilities in the particular neighborhood/local area. Integration is a major goal of a rehabilitation approach.

Family Support:

1. Families need to have respite services available either in the home or in a respite program where the family member can stay.

2. Families and consumers need more support in making a successful transition from the family home to a more independent setting.

3. Professionals need to use the knowledge of family members in selecting housing options and in planning housing and supports.

4. If families wish to organize and/or finance their own housing for people with psychiatric disabilities, there should routinely be services available which support consumers in that housing.

IV. Training and Public Education Recommendations

1. Direct staff need training in the following areas:
   - a psychiatric rehabilitation approach to housing
   - ways to support people on-site or in their housing, regardless of where they live
   - helping people control symptoms and behavior that may cause the community to fear or reject them
   - management aspects of housing
   - accessing housing including working with realtors and the housing community

2. Administrators need training and technical assistance focused on housing needs, and on strategies for meeting them.

3. A national meeting of state housing and mental health officials should be convened to identify financing vehicles for meeting housing needs, such as through-state bonding authority

V. Research Recommendations

1. There is a need to package and disseminate what is known about how to best help meet the housing and support needs of people with psychiatric disabilities.

2. Research is needed on community reactions to people with psychiatric disabilities living in the community, and how to increase acceptance.

3. Within the field of rehabilitation, there is a need to establish a journal specifically devoted to housing and supports for people with psychiatric disabilities.

4. Data is needed on consumer preferences about where they want to live and what their special needs are related to housing.

5. Data is needed on the effectiveness of various combinations of services and settings providing housing and support for people with special needs in addition to a mental illness (e.g., deafness, substance abuse, mental retardation, and so forth).

6. Research is needed on the most effective strategies and supports which assist consumers to select, acquire and maintain decent, stable, affordable housing.

VI. Legislation and Funding Recommendations

Federal:

1. The Department of Housing and Urban Development (HUD) resources should be block-granted to states. It's very important for the federal government to provide capital funds to mix with state funds, and to give state and local programs flexibility.

2. The number of HUD rent subsidies (all forms of Section 8) should be increased substantially.

3. HUD should be principally a funding agency, and not be involved in development and management functions (especially of services), all of which are state and local responsibilities.

4. There should be a high level group of mental health representatives to work with HUD to revise their regulations related to people with psychiatric disabilities.

5. All low-income housing programs (e.g., the Section 22/d4 program) should be available to people with psychiatric disabilities, who also have low incomes.

6. Funds for housing for homeless people should be oriented toward stable housing, as opposed to transitional approaches.

7. The independent living programs in Vocational Rehabilitation should be actively encouraged to specifically include people with psychiatric disabilities.

8. Federal fair housing legislation needs to include a proscription against housing discrimination toward people with psychiatric disabilities.

9. Fair housing legislation should also include a proscription against using zoning to exclude programs for people with psychiatric disabilities.

10. States need to expand their role in capital funding related to housing.

11. States and the federal government should develop significant incentives for the private sector to become involved in housing development from which people with psychiatric disabilities can benefit.

12. States should play a greater role in developing affordable housing through their own rent subsidy programs similar to HUD Section 8.

13. There should be a national policy on the basic right of all citizens, including people with psychiatric disabilities, to decent, stable, affordable housing.

14. Every state mental health authority should develop a plan to meet the housing needs of consumers. The plan should be prepared in collaboration with consumers, families, providers, and public and private housing agencies.

Coordination of Efforts Between Vocational Rehabilitation and Mental Health Systems

Joan T. Barker

Mental Health and Rehabilitation Agencies – national, state, and local, have let the old barriers to cooperation prevent them from seeing the numerous advantages in a cooperative working relationship. The intent of this paper is to explore these barriers and point out practical and rewarding paths to collaboration.

This discussion is offered as an experiential eisegesis, not necessarily based on documentation or prior literature. It is prepared with the hope that views attained working with both systems will stimulate further examination, research, observation, recommendation, and cooperation between agencies. As always, the ultimate goal must be to offer each human being the dignity of using his or her abilities to live as well as possible, thereby creating a more peaceful and actualized world which can be a "home" for all.

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Mental health and rehabilitation have evolved from different perspectives leaving each with differing points of view regarding their respective roles and responsibilities in serving the mentally ill. Differences in history, language, mission, accountability measures, organization, professional values, public image, legislation, advocacy, and funding unfortunately have created barriers between these two professions which complicate and discourage working together.

The mentally ill, and especially persons with long-term mental illness, constitute a significant and growing percentage of our country's disabled, and we cannot ignore our responsibility to give attention to this population. This group is not likely to magically disappear and the costs of this disability are continually escalating to impose a significant drain on our nation's economy in both dollars and manpower. With prevailing issues such as homelessness, deinstitutionalization, rising crime rates, depletion of social security funds, uncontrollable medicaid costs, loss of production hours in business and industry, child abuse, spouse abuse, and substance abuse, Congress must give increasing attention to the provision of services which facilitate community adjustment and rehabilitation for the long-term mentally ill.

The efforts to deal with mental illness -- to offer protection, comfort, or care -- can be traced as far back as the recorded history of mankind. Whether we recall the biblical "casting out of devils" or the "ship of fools", we soon realize that persons unfortunate enough to develop mental illness have aroused feelings in others of empathy, fear, chaos, and bewilderment.

Many of us who work in this field are tempted to feel that history has dealt us an unkind and irrational burden of stigma which must be addressed in addition to an already overwhelming task of system design and implementation. However, upon retrospection we realize that this stigma is a perfectly natural, although a troublesome, human reaction.

History documents similar reactions to major plagues and diseases which have seriously threatened the survival of mankind. This instinctive reaction of man to protect his survival must be viewed in the context of time. Once we have found a solution to combat mental illness, society's fears will shift to other victims of frightening disease and misfortune. Until then we must live with man's natural defenses which are truly both a blessing and a curse.

Since we do not know what causes mental illness or how to cure these "diseases", our history continues to document varied approaches leading in divergent directions and spearheaded by enthusiastic therapists who believe a "cure" is eminent. Most of these movements, although originally fueled by genuine efforts to offer humane care, have gone awry.

One such example was the asylum movement initiated during the early 1800's and inspired by leaders such as Dorthea Dix. Asylums were established to offer humane care to rescue, feed, clothe, and protect persons with mental illness who wandered the streets and slept in doorways or cellars. This movement promised a cure and was not imagined to reach the overcrowded, dangerous and punishment-oriented conditions which developed by the 1880's and 1890's.

In an effort to resolve this dilemma, a new system emerged in the 1920's which proposed the use of acute community hospitals with institutions, usually state-operated, used as a backup for necessary long-term care. Unfortunately, most of the funding and administrative power remained in long-term institutions and acute care community hospitals became an almost certain path to long-term institutionalization.

By the early 1950's, institutions were so overcrowded and patient "care" so deplorable that punishment "therapies" abounded in spaces where there was not room to walk between beds and patients had absolutely no personal living space. It was during the decade of the 1950's that neuroleptic medication became available -- a revolution in "treatment" for persons with serious mental illness.

Psychiatry suffered throughout this period of transition. there were few rewards for medical doctors to choose a specialty where cures were unknown, pay and status were low, stress was high, and stigma stifled both patient and professional. Consequently, psychiatrists were few and many who were qualified gravitated to work with the "worried well" who presented greater hope of recovery and the ability to pay. Psychologists, social workers, and nurses filled the ranks to meet the need for professional manpower, vocational rehabilitation units were established in institutions, and mental health service delivery spawned diverse programs, philosophies, and techniques to seek a "cure."

Although no one knew what to do for persons with mental illness, it was apparent that the overcrowded institutions were inhumane, expensive, and chaotic. By the early 1960s, the use of medications and the philosophical principle referred to as normalization were used as a base in designing care. Many institutions developed "therapeutic communities" which simulated actual community life. However, normalization principles pushed treatment further toward the community by recognizing the value and dignity in all human beings, including persons with disabilities, and their inherent rights as citizens to have the opportunities to achieve meaningful lives through productive activity and community participation.

Pursuit of the least restrictive environment led to deinstitutionalization, a broader reform movement with two main features: a plan for a full range of community-based services and a reduction of the population in state institutions.

In 1963, President John F. Kennedy demonstrated his unusual capacity for vision and sensitivity in addressing our nation's needs by spearheading comprehensive legislation which passed Congress as the Community Mental Health Centers Act. The Community Mental Health Centers (CMHCs) were designed and funded to care for persons leaving the institutions so that they might live a "normal" life in the "least restrictive setting." There was also optimism that through early intervention CMHCs would prevent future generations from ever needing hospitalization or becoming institutionalized and thereby "manage" the disability of serious mental illness in our country.

The CMHCs have done a tremendous job in accepting this shift from inpatient to outpatient care. In 1955, state hospitals accounted for 49 percent of all psychiatric episodes, compared with only nine percent in 1977. (Ahr and Holcomb, 1985) However, during the same time period, the overall need for treatment seemed to explode as treatment episodes increased from 1.7 million to 6.9 million, with the greatest expansion occurring in outpatient services (from 23 percent in 1955 to 70 percent in 1977). Some of the growth in outpatient services can be attributed to expansion of aftercare for patients discharged from state hospitals. However, most patients receiving outpatient services have had no prior psychiatric care. (Thompson, Bass, and Wilkins, 1982)

Problems created by this explosion in numbers of persons needing services in the community were further complicated by an overall systems inability to shift staff and funds from institutions to CMHCs. Although CMHCs have worked diligently to secure funds and be responsive to community need, many individuals remain unserved or underserved. A population of persons who are disabled by mental illness once again wander about homeless, much as they did in the early 19th century when asylums were thought to be a solution.

The deinstitutionalization movement has been surrounded with controversy, but most agree that the best direction lies in developing responsive and effective community services rather than in expanding and proliferating institutions. The current controversy centers around the best design for community care and giving attention to the most severely disabled. In a 1984 position paper, the National Association of State Mental Health Program Directors stated: "Recovering from a period when community mental health appeared to have failed the inordinate expectations of professionals and the public, state and local programs are re-establishing a sense of integrity by trying to respond to the needs of the most troubled--and troubling--mentally ill in the community."

During the 1940s and 1950s, important consumer movements were also developing. Fountain House was the first psychosocial rehabilitation center established in the United States. It was developed in the early 1940's by a group of patients at the Rockland State Hospital in New York who met on a regular basis to help each other through the transitional phase of leaving the hospital and re-entering the community. A volunteer worked with the group and assisted them in organizing services and developing a more formal agency. Fountain House developed vocational, social, and residential services using a total rehabilitation approach with the philosophy that all clients are "members" of the Fountain House community and that everyone involved is accepted equally. Members helped one another in daily living activities and worked together in mutual support.

Since that time, many other notable psychosocial programs have developed along with other programs and businesses based on related models which are also consumer operated. The appearance of highly visible consumer role models, such as Ralph Nader, have boosted the morale and advocacy of all persons with disabilities and their family members during the past three decades. They can now voice their needs with the dignity and admiration attributed to self-advocacy and responsibility for one's own health and fortune.

The most recent and promising movement in Mental Health systems began in 1977 with the Community Support System Program's (CSP) birth at NIMH.

The "community support program" concept went beyond the mental health service needs of persons with long-term mental illness and proposed a range of services, supports, and opportunities necessary to maintain individuals in the community. Accordingly, the essential components of CSP include psychosocial rehabilitation, supportive housing, assistance in meeting basic human needs and obtaining entitlements, etc. The CSP concept also addresses the need for the assumption of responsibility for persons with long-term mental illness by service agencies within local communities and for the coordination of services to clients through a variety of case management activities (Stroul, 1982). This program's design and philosophy is grounded in the same basic tenets as traditional rehabilitation philosophy. CSP lends itself to increased opportunities to work cooperatively with vocational rehabilitation in recognizing, supporting, and maximizing the abilities of individuals disabled by long-term mental illness to live more productively and/or more independently in the community.

Vocational Rehabilitation's Historical Perspective

Vocational Rehabilitation first began after World War I and was spurred by the need of the nation's wounded and disabled to resume active and productive lives. The program was deeply rooted in the work ethic and the determination of returning soldiers to "pull themselves up by their own bootstraps." Rehabilitation was thought of as a necessary and noble mission.

It was not until 1943 that rehabilitation was legally mandated to serve persons with mental disabilities as well as those with physical disabilities. However, when one considers that this expansion took place about ten years before neuroleptic medications, it is apparent how progressive such a mandate must have been.

In the 1950s, state Vocational Rehabilitation programs began to negotiate cooperative agreements with Mental Health systems to place VR units and halfway houses in state hospitals. These units usually included home economic areas which taught activities of daily living and work facilities offering evaluation and training. During these years, VR services developed a substantial knowledge base and served as one of the most realistic service linkages to the community. Rehabilitation professionals often found themselves competing for promising clients with hospital treatment services and were often given the most seriously disabled. This phenomenon actually strengthened rehabilitation programming as the philosophy of maximizing a person's abilities countered the mental health models (especially the medical model) of documenting illness, disease, and dysfunction.

As CMHCs were established, Vocational Rehabilitation in many states negotiated inclusion of a full or part-time team. The Rehabilitation Services Administration funded several long and short-term training programs to teach rehabilitation skills to this developing workforce.

At about the same time, NIMH began the CSP program and funded training for nationwide participants at Fountain House. The National Institute of Mental Health and the National Institute of Rehabilitation Research, now NIDRR, funded two research and training centers focused on mental health rehabilitation. This combination of events resulted in a proliferation of diverse rehabilitation programming and further developed a base of knowledge for psychiatric rehabilitation. In 1977, there were 18 psychosocial rehabilitation clubhouse programs in this country and by July of 1983, there were 180. (Mosher, 1986)

The availability of community resources fueled the growth in numbers of persons with long-term mental illness referred to and served by VR agencies. Although many states and localities had cooperative programming, it was not until 1982 that the first cooperative agreement was signed at the federal level between NIMH and RSA.

Rehabilitation, like the Mental Health field, was also influenced in the 1970s and 1980s by consumer demand and activism. National coalitions and associations began to advocate for more sophisticated and tailored services essential for the rehabilitation of special populations. Consumers and families interested in long-term mental illness were no exception. Definitions within legislation which had been restrictive were expanded to include all disabilities, and civil rights were greatly clarified by legislation and the courts.

The 1986 amendments of the Rehabilitation Act specifically included persons with mental disabilities as eligible for Supported Employment and Independent Living programs. This was particularly significant since these were new rehabilitation programs which were designed to serve those who could not readily train for competitive employment. In fact, these additions to the rehabilitation field allowed the VR professional to actually meet the MH professional as they succeeded in readying the client for work. The legal boundaries of both programs had conceptually come together offering the hope that existing services would follow suit.

Language

In today's ad-conscious society, we know that words create images which often propel thought and action. Therefore, the words we use to communicate our craft, skills, expertise, and intent are crucial in determining our direction.

Although today's practitioners may sometimes scoff at the use of long-term mental illness to replace chronic mental illness or persons with disabilities to replace the mentally handicapped, they will easily concede that we no longer need "witch doctors to rid the possessed of their demons."

As time moves on, our language has reflected our philosophy of service and the level of responsibility we expect the doctor/patient or counselor/client to assume. Many

professionals have come to refer to persons they work with as "consumers" or "members" in order to convey that these individuals also work with them in accepting responsibility and managing their own lives. Our words actually convey our respect for the individual served, be it positive or negative, as well as for one another.

Mental Health: Theory, Science, and Practice

Mental Health professionals (Psychiatrists, Psychologists, Psychiatric R.N.'s, and MSW's) have traditionally been trained with a strong emphasis placed on the medical model.

> "Briefly stated, psychoanalysis was imported from Europe and was embraced with open arms here almost from its inception. The historic gathering of renowned psychiatric figures (including Freud, Jung, and Meyer) at Clark University in Worcester, Massachusetts, in 1912 is reflective of how early on psychoanalysis's importance was recognized on this side of the Atlantic. Between that time and the mid 1950s it gained momentum and adherents. Its purview expanded from an initial focus on the office treatment of neurosis to one that included the hospital-based treatment of psychosis as reflected in the writings of Fromm-Reichmann, Searles, and many others. Unfortunately, this expansion of interest and followers brought with it great expectations not unlike those currently surrounding biological psychiatry. In the early 1950s it was widely hoped that psychoanalysis would be able to offer the "silver bullet" that would conquer madness once and for all. As will likely be the case with at least the reductionistic portion of biological psychiatry, psychoanalysis's implicit promise went unfulfilled. Disappointment set in, especially among those with the most exaggerated expectations. These expectations could be shifted to the new drugs that came on the market at about this time. Psychoanalysis was no longer seen as the treatment of choice for psychiatry's most disturbed and disturbing patients. This shift in view is attested to by the change that has occurred in what are defined as a good psychiatric chairperson's qualifications: in the late 1950s and early 1960s analytic training was almost a requirement to be qualified to take a chair in psychiatry at a prestigious university. Today it is required that chairpersons be biological researchers -- quite a contextual change in only 20 years. Chairperson needed, non-biologists need not apply is the order of today.
>
> In brief, community psychiatry as a movement began in the late 1940s with psychiatric professionals (led by an APA president) who were very critical of the inhumanity of the custodially oriented state hospital system. This led, eventually, to the formation of the misnamed Joint Commission (named "Joint" because of its original APA/AMA sponsorship) that ultimately contained representatives from a dozen or more organizations. In 1961 this commission produced a landmark report, "Action for Mental Health." (Joint Commission on Mental Illness and Health, 1961)
>
> The report called for gradual replacement of large state hospitals with smaller, local community-based institutions that would emphasize outpatient, community-oriented, active treatment. A most uncharacteristic governmental event then took place; the President of the United States read this Commission's report in its entirety! (Ewalt, 1984)
>
> This document provided the background for Kennedy's February 1963 speech and the subsequent CMHC legislation, passed and signed in October of that year. Unfortunately, many social, political and economic events were to shape and reshape this reform movement until finally, in 1981, the last piece of CMHC legislation (the Mental Health Systems Act of 1980) was repealed as part of the Reagan administration's Omnibus Budget Reconciliation Act of 1981. This history has been ably documented by Foley and Sharfstein (1983)." (Mosher, 1986)

Today community psychiatrists are scarce since there are few financial incentives for working in the community and those who work there spend most of their time prescribing medications.

Mosher continues to explain that one of the factors which affects psychiatry's relationship with nonmedical professionals and programs is:

> "its strong research and ideological thrust toward viewing psychiatric problems as real diseases. This is a further extension and reification of the original *as if ill* metaphor that created the category of *mental illness.* This is reflected most clearly in DSM III's symptom-in-the-individual focus. Reactions and disorders have been replaced by diseases. Contextual factors that have been shown to affect psychiatric assessment (Mosher, 1978) have no place in DSM III. Another impact relevant to establishing rapport between community support programs and psychiatry is an attitude among some psychiatrists best embodied in the phrase *you can't talk to disease.* Although DSM III tars all problems with some disease brush, psychiatrists tend to view schizophrenia and major affective disorders as *real* diseases, whereas there would be less agreement about whether or not what used to be called neuroses are true diseases. Hence, talking with persons in the latter categories might be useful. In practice this leaves talking with the most disturbed and disturbing individuals to non-psychiatrists -- i.e., the kinds of persons working in Community Support Programs. In this context Community Support Programs will feel themselves being pushed into a second-class-citizen status not unlike their clients. Psychiatry will want to be *responsible* for these patients but will not see them as worthy of any serious talking with; ergo, talk will be the purview of CSPs. Since it has already been determined that this talk is not curative but sometimes necessary, it can be done by lesser beings if they're under medical control and supervision since, after all, the doctor bears ultimate responsibility for the patient's care." (Mosher, 1986)

Psychiatry has been transformed since the 1950s by the development of powerful and effective treatments for

psychosis: the neuroleptics for schizophrenia, the antidepressants for depression, and lithium for bipolar disorder.

Recently the PET scan arrived hard on the heels of the CAT scan and has been followed by the NMNR. As assays and techniques have become available, they are quickly applied to persons manifesting long-term mental illness.

> "This technological growth has created both a new *scientific* biological psychiatry and a psychological set of great expectations from it. The *silver bullet* that will allow us to put to rest forever the perplexities of madness is feverishly sought. Hopes are high that at last the "schizococcus" will be isolated and a vaccine against it developed. While this description may be slightly exaggerated, it is consistent with our culture's prevalent belief in the power of technology to solve problems." (Mosher, 1986)

Non-psychiatrists who are mental health professionals have also been greatly influenced and thrown about by the evolution of psychiatric trends. They have struggled to find their place in the treatment scheme, offer credible services, and at the same time maintain adequate income. Like psychiatrists, many have chosen to move to more lucrative private practice while others have remained in the community to fill the serious manpower shortages. This has left non-psychiatrists to fill important administrative and leadership positions which determine directions and philosophy for community programming. At the moment, it appears that the general relationship between psychiatry and community programs is minimal.

Those left to deal with the realities of community living for persons with serious mental illness have become increasingly practical about their own limitations and the everyday needs of their consumers.

In a 1984 position paper of the National Association of State Mental Health Program Directors, it was stated: "We must acknowledge our limitations, and acknowledge what we don't know: A - the etiology of most mental illnesses; B - how to cure the major mental illnesses; and C - the long-term effects of some psychotropic medications."

Acknowledging what is unknown marks a crucial step in clarifying the professional's responsibility to consumers. It is the first step in determining what role is appropriate for professionals in offering consumers the support services and opportunities to live as well as their health and abilities permit.

Much in the same vein, the Community Support Services model is based on the provision of 10 service areas which are basic rehabilitation and support services that professionals can provide. (Turner and TenHoor, 1978)

Mental health theory, science, and practice has evolved primarily from one of introspection to one with medical, psychoanalytic, biological research, community support, and rehabilitation components.

Vocational Rehabilitation: Theory, Science and Practice

Vocational Rehabilitation Professionals have traditionally been trained in counseling psychology theory with a strong emphasis on the medical model and medical treatment as well as applied behavior theory and functional analysis and planning. It is almost as if Vocational Rehabilitation chose an eclectic path and borrowed from medicine, social work, psychology, disability determinations, business and industry, engineering, and anyone else who could offer information useful in providing services to persons with disabilities. Needless to say, the task of serving all types of disabilities is a complicated and demanding assignment.

Since the bottom line of Vocational Rehabilitation has been competitive employment, traditional theories have frequently been discarded in search of practical methods and new theories to prepare, place, and maintain a client in employment. Normalization theory of the 1960s had a profound influence on the delivery of rehabilitation services. This movement along with the migration of consumers to the community stimulated new methods and an expanded knowledge base in psychiatric rehabilitation, functional assessment, and job placement techniques. An exception to this method may occur with the client disabled through long-term mental illness who can be trained in work which is not considered a final placement (e.g., as in the Transitional Employment Model or TEP), but the goal of placement for these persons who are severely disabled into an integrated setting remains the same.

The addition of supported employment programs represents a new model of "place" and "train" as opposed to the traditional one of training before placement. Supported Employment also provides for ongoing support and integrated work with non-disabled individuals producing valued goods or services for a fair wage.

Independent living programs are probably the most radical addition to the field of rehabilitation since the goal of competitive employment is not a required goal for the individual served. However, this addition truly exemplifies the practicality of rehabilitation and the field's responsiveness to the needs of consumers with disabilities.

Rehabilitation has evolved to a point where a solid and ever-growing body of knowledge exists that is uniquely "rehabilitation". After a history of borrowing from others, rehabilitation is now established as a true profession offering ongoing research and unique service and support to all persons with disabilities. It is extremely important that today's rehabilitation practitioners know they are "professionals" in their own right and have "professional expertise" with which to serve their clients.

Since mental health practice has moved toward the widespread use of rehabilitation principles through CSP, psychiatric rehabilitation, and psychosocial programs, Vocational Rehabilitation currently has a unique opportunity to work with both consumers and Mental Health professionals who wish to extend rehabilitation opportunities and place more emphasis on employment goals.

Incidence and Demand

According to National Center for Health Statistics figures, in the civilian non-institutionalized population of the U.S., there are 18.4 million people with orthopedic impairments or deformities; 17 million persons with hearing impairments; 8.2

million with visual impairments; 2.1 million with speech impairments; 26.8 million with arthritis; 24.3 million with hypertensive disease; 16.4 million with heart disease; 1.6 million missing extremities or parts of extremities; and 1.2 million who are partially or completely paralyzed (Mathematica Policy Research, 1984, p.2). Another study found that there are approximately 5.7 million mentally retarded persons in the U.S., 2.4 million persons with epilepsy, 950,000 who have cerebral palsy, and about 95,000 with autism. (EMC Institute, 1979)

Goldman, Gattozzi, and Taub, 1981, estimates that some three million Americans have been diagnosed as having a severe mental disorder, with the number of individuals with chronic mental illness placed at between 1.7 million and 2.4 million, including 900,000 who are institutionalized. The National Institute of Mental Health, however, estimates prevalence in a 1985 report as 29.4 million (18.7 percent of the population) of adult Americans who suffer from one or more mental disorders in any six-month period. Much of the discrepancy in numbers might be explained by their estimate that fewer than 29 percent of Americans suffering from any mental disorder seek mental health services from mental health specialists or general physicians. (NIMH, "Mental Health, United States 1985")

This report (NIMH, 1985) also documents:

Prevalence

- For males, the most frequent disorders are alcohol abuse/dependence, phobia, drug abuse/dependence, and dysthymia.
- For females, the most frequent disorders are phobia, major depressive episode without grief, dysthymia, and obsessive-compulsive disorders.
- Fewer than one-fifth of the individuals identified with any mental disorder in a six-month period used any mental health service from either mental health specialists or general medical physicians.

Service Trends

- Organizations providing mental health services rose from 3,005 to 4,302 between 1970 and 1982 -- an increase of 43 percent.
- There were 53 percent fewer psychiatric beds available in 1982 than in 1970.
- State and county mental hospitals accounted for about 57 percent of all psychiatric beds in 1982, compared with 79 percent in 1970.
- After tripling between 1969 and 1979, day treatment additions decreased slightly in 1981.
- Persons aged 25 to 44 accounted for the largest percentage of admissions to all inpatient psychiatric services in 1980.
- Most admissions to inpatient psychiatric services were voluntary, except for those to state and county mental hospitals, where the largest percentage were involuntary non-criminal commitments.
- For each type of inpatient psychiatric service, more than 70 percent of admissions were re-admissions for inpatient psychiatric care.
- Schizophrenia was the most frequent primary diagnosis for admissions to state and county mental hospitals and public and multiservice non-federal general hospitals; affective disorders, for admissions to private psychiatric hospitals and nonpublic non-federal general hospitals; and alcohol-related disorders, for admissions to VA medical centers.
- Median days of stay for admissions to state and county mental hospitals, VA medical centers, and private psychiatric hospitals were very similar and considerably longer than median stays for admissions to nonpublic, public, and multiservice non-federal general hospitals.
- Between 1970 and 1980, median days of stay for admissions (excluding deaths) to state and county mental hospitals decreased from 41 to 23 days but remained relatively stable in both private psychiatric hospitals and non-federal hospitals.
- The distribution of admissions by psychiatric diagnosis remained relatively stable between 1970 and 1980.
- In 1982, more than 390,000 full-time equivalent (FTE) staff were employed in U.S. mental health organizations.
- The number of FTE psychologists, social workers, and registered nurses employed in mental health organizations increased consistently between 1976 and 1982. However, the number of FTE psychiatrists and other physicians decreased between 1976 and 1978, before increasing in 1982 to levels higher than in 1976.
- In contrast to a decrease in state and county mental hospitals, the total FTE staff in private psychiatric hospitals nearly doubled between 1972 and 1982.

Suicide

- A total of 587,821 persons in the United States ended their own lives by self-inflicted injuries between 1958 and 1982. Although overall suicide rates increased between 1958 and 1978, they leveled off between 1978 and 1982.
- Suicides by persons under age 35 increased markedly between 1958 and 1982 from 19 to 41 percent. Suicide was the third leading cause of death for this age group in 1982.

The Research and Training Center at the Albert Einstein College of Medicine is currently conducting a study which uses a one percent nationwide sample of all cases from 1977 to 1984. (unpublished) In an overview of Vocational Rehabilitation services provided by state agencies with RSA funding, they have found:

Einstein data analysis indicates that referrals of persons who are psychiatrically disabled as well as general referrals declined significantly from 1977 to 1984. However, of those referred, both groups showed a significant increase in referrals that were severely disabled, with the severely psychiatrically disabled escalating most. The psychiatrically disabled ac-

Table 1

	Psychiatrically Disabled		Non-Psychiatrically Disabled	
	All	Severely Disabled	All	Severely Disabled
Average Referrals Per Year	173,475	81,425	536,638	192,300
		of those		
Percent Accepted for Services[1]	51.3%	58.3%	41.3%	70.7%
		of those		
Percent Rehabilitated[2]	54.2%	50.7%	66.0%	62.5%
		of those		
Percent Employed Competitively[3]	84.5%	77.5%	75.1%	65.9%

1 Number accepted for services divided by total referrals, multiplied by 100.
2. Number rehabilitated divided by number accepted for services, multiplied by 100.
3. Number rehabilitated to competitive employment divided by number rehabilitated, multiplied by 100. For example, other than homemakers, self-employed or sheltered workshop employees.

cepted for services also showed a marked increase from 1982 to 1984, whereas the non-psychiatric disabled showed only a slight increase in acceptance. Both the psychiatric and the non-psychiatric data exhibited a drop in the number rehabilitated from 1977 to 1984. However, it was clear that the psychiatrically disabled had a 9.4 percent greater chance of being competitively employed through rehabilitation services than did the non-psychiatrically disabled.

None of these figures were startling in view of the population shifts and policy changes occurring in Vocational Rehabilitation and Mental Health programs during those years. The data confirms, however, the advantages of working together to assist consumers in achieving competitive employment.

An extremely important area which Vocational Rehabilitation fails to give sufficient attention is the high "risk" for persons with physical disabilities to experience mental illness. This group frequently goes without care as a result of their isolation and the attribution of symptoms to a physical disability. Consequently the population of individuals with substantial degrees of disability is steadily growing, setting the stage for related mental health problems to escalate.

Researchers at Boston University, Center for Rehabilitation Research and Training in Mental Health, assert that mental health needs of people with severe physical disabilities are seriously underserved. They point out that public policy exists for the medical and vocational rehabilitation of this population but that none exists with respect to the mental health services needed by many members of the group.

They report:

- Many disabled people are described as "seclusive, inactive, and housebound."
- Many severely disabled people have poor self-concepts.
- Social contacts for severely disabled people often are limited to family members and caregivers.
- Spinal cord injured people, as a group, show increased mortality rates because of self-neglect.
- A high proportion of long-term stroke survivors manifest social disability despite physical restoration.
- A significant incidence of alcoholism exists among rehabilitation clients.
- A sample of children with disabilities showed a rate of psychiatric disorders nearly twice that of non-disabled children.
- Psychological test data from physically disabled applicants for Social Security benefits show that 35 percent to 44 percent have been diagnosed as having moderate to severe psychoneuroses or personality disorders.

"Thus, the literature suggests that people with severe physical disabilities may have a wide range of emotional problems and needs related to coping with disability. These include managing stigma, disruption of family life, and increased suicide risk, as well as psychological problems found throughout the general population." (Thurer and Rogers, 1986)

According to the 1980 census figures, almost 63 percent of the total number of persons reporting disabilities were not in the labor force (i.e., neither employed nor seeking employment). Nearly one in five of all people not in the labor force

report a work disability (19.1 percent), while only 4.4 percent of all who are employed report a work disability.

Census figures also indicate some correlation between work disability and poverty. Of the 12.9 million persons of working age reporting the presence of a work disability, 2.6 million (or 20.1 percent) have family incomes that are below the federal poverty threshold. This is more than double the 9.1 percent rate of the general population which has a family income below the poverty line.

Potentially, the most profound trend of the late 1980s may be the emergence of a critical mass of young, highly disturbed adults. The change in the characteristics of the mentally ill in the community represents the realization of the policies of the 1960s and 1970s. While many persons associated deinstitutionalization with the movement of the state hospital patients back to the community, the priority patient of the future probably will never have been treated in a state hospital but will have the clinical profile previously associated with long-term hospitalization. Ironically, no one should be startled by the development of this patient group in the community. There is no indication that the incidence and prevalence of severe mental illness has changed but, instead, that the primary location of the environment in which the illness is experienced has been altered. (Surles, 1987, p. 221)

In a 1984 study of 100 clients admitted to the partial care program of a community mental health center, McCreath found the majority to be young, single, well-educated adults with chronic psychiatric disorders. These clients are frequently hospitalized in other than state or county hospitals. This article supports the hypothesis that a new generation of chronic psychiatric patients exists. This data has significant implications for planning mental health, rehabilitation, and transition programming in the schools. Data is just beginning to emerge on children, but Mathematica Policy Research, 1984, estimates 339,629 children who are seriously emotionally disturbed. (p. 101) If we add the number of those who are moderately disturbed as well as the unidentified children in need of mental health care, the numbers would surely escalate.

Advocacy

Consumers, family members, and a wide variety of professionals have become increasingly active in diverse advocacy efforts in recent years. The number of advocates in consumer ranks is presently unknown, although recent growth is evident. The number of members in the National Alliance for the Mentally Ill is estimated to be 80,000 with an estimated growth of 15 percent each year. (Hatfield, 1988)

Professionals in mental health, rehabilitation, and related fields belong to such diverse and numerous organizations that it would not be possible to estimate how many are advocates for this population. However, two major coalitions are dedicated to national advocacy on behalf of persons with disabilities, including the disability of mental illness. The National Rehabilitation Coalition represents 40 major associations, and the Consortium of Citizens with Disabilities represents 56 major organizations. These coalitions include professional, consumer, and family groups such as the National Rehabilitation Association, the National Mental Health Association, the International Association of Psychosocial Programs, the National Alliance for the Mentally Ill, the National Association for Retarded Citizens, the American Association for Mental Retardation, etc. many organizations belong to both coalitions.

Each organization is also active in its individual advocacy efforts which cover a wide range of efforts in legislation, funding, education, media, business and employment, accessibility, public speaking, awards and recognition, foundation development, etc.

Efforts have become so widespread that there is a place for everyone to contribute. However, there is always much more to be done as long as stigma, discrimination, funding shortages, and legislative or policy flaws deter persons with mental illness from living and working as well as their abilities allow.

Stigma

The National Association of State Mental Health Directors (1984) cited discrimination in funding and programs for the mentally ill as the most significant barrier they face and stigma as the second. They described stigma related to: A - zoning or other public restrictions on housing for the mentally ill; B - employer attitudes against the mentally ill; C - defenses of families against appropriate support; D - reluctance of families to advocate for mental health programs.

The negative myths and misinformation prevalent in our society regarding mental illness can be as damaging, isolating, and anxiety-provoking to the individual as the illness itself. These myths are often passed from generation to generation or perpetuated by the media.

Movies, television, and other art forms often portray the person with mental illness as violent, evil, and conniving. Although it is well known that only one percent of this population are actually responsible for dangerous and criminal behavior, this myth persists.

Employers and potential employers are among those in the general public with the same misunderstandings about mental illness. Many who are ready for work must hide their mental health histories to avoid discrimination.

Dunn (1982) delineates very real factors which increase stigma and damage both self-concept and public image for a person with long-term mental illness when unemployed. Three major factors of long-term unemployment contribute to the scenario: 1. the loss of time structure; 2. loss of social participation, friendship, and support; and 3. loss of identity and self-esteem. The complications generated from such loss tend to overlap with typical mental health symptoms and exacerbate both dilemmas.

In our society, social status is largely determined by occupational achievement. Employment not only provides an individual with income and a standard of living, but time structuring, social interaction, personal esteem, as well as personal identity and status. The loss of employment causes an individual to go through a grieving process similar to the loss of a relationship or death. For persons with a mental illness, this process often begins after being hospitalized once or twice and returning to the same job, or when similar work is unavailable. When unemployment persists, the long-term results of

chronic unemployment set in. Studies show this point is often reached in approximately two years and is characterized by hopelessness and apathy.

In spite of the disabling effects of stigma and illness, many people with mental illness do recover enough to work without disabling interruptions. Even those with the most serious illness have regained the ability to work and live successfully in the community. It is difficult to estimate how these numbers would grow if such individuals were given the dignity and support all human beings deserve.

Mental Health: Legislative Authority and Mission

Although Mental Health program design has been influenced strongly by federal legislative mandates of the past, today's program administrators are primarily left to influence legislative direction in their home state by working with elected officials or governing boards of local programs.

"The increase in state policy influence and control was required with the Federal Budget Reconciliation Act of 1981. When the 1981 Budget Act replaced the Mental Health Systems Act, states were given extensive flexibility to define the role and functions of community mental health organizations. Most states, especially those with large community mental health center programs, received less funding through the Alcohol and Drug and Mental Health Block Grant than had previously been distributed directly to community mental health centers. However, most states have actually increased funding for mental health services during the period of federal retrenchment. Sates are asserting greater influence over local centers and most have established or reaffirmed priorities for state funding for services to former state hospital patients and the chronically mentally ill. Most states appear to be continuing a policy of contracting rather than directly operating community mental health services, but there does not appear to be a high priority given to previous federal concepts of community governance." (Surles, 1987)

The freedom of states to choose their own design for implementation initially appears to be advantageous. However, the problems far outweigh the advantages. Given the scarcity of resources, programs have become so diverse and disjointed that "continuity of care" is a major issue both within each state and nationwide. Further, there is no single funding source to suggest consistent programming, and funds are often targeted to the "crises of the day".

Legal rights of consumers to access and benefit from services have also been vague and are usually decided through court decisions of precedence. Interpretations of program policy frequently change with changes in major administrative personnel. Talbott, 1985, observed, ". . . in moving treatment from one single institution -- the state hospital -- to many community facilities and agencies, we have lost the element of "point responsibility" for treatment and care of the mentally ill. It is by now abundantly clear that no longer is any single person in charge of the psychiatric "system," or responsible for the entire patient population, or any segment of it, or indeed even any individual patient." However Mental Health administrators continue to do their best to design and implement adequate programs.

The National Association of State Mental Health Directors recognized this dilemma in their 1984 position paper as they geared their discussion to setting parameters. Their consensus was to limit efforts to: A = preventive efforts; B - treatment efforts; and C - rehabilitation efforts; and not assume responsibility for broader social problems. (Example: unemployment, the homeless, poverty, civil rights issues, criminality.)

One of the primary reasons that the leadership of NIMH's CSP movement has been so effective is that they addressed relevant issues, clarified program values, defined the goals and strategies, identified the population, and recommended the provision of practical services that professionals were capable of delivering.

In summary, authority for mental health services is usually defined by professional and program licensing and regulation, but the mission itself falls short of consensus and is characterized by numerous types of professionals attempting to advance their best effort to provide service. Resolving systems problems appears to be the most critical challenge facing the mental health field today.

Vocational Rehabilitation: Legislative Authority and Mission

Since authority, funding, and regulation for Vocational Rehabilitation programs is directly derived from the Rehabilitation Act of 1973, as amended, the parameters for rehabilitation services are relatively clear. This consensus of direction is of considerable advantage, although it often instigates accusations that Vocational Rehabilitation is bureaucratic and laden with red tape.

Vocational Rehabilitation usually knows what they can or cannot do, and will usually count and document all that is done. This creates a distinct advantage for the Rehabilitation Services Administration, State Vocational Rehabilitation programs, and various advocates when they return to Congress to testify on accountability and the need for additional funding.

Another excellent feature of the Vocational Rehabilitation process is the individual latitude allowed for a counselor and client to work toward goals. This is an astonishing achievement in a highly organized and well-documented system. The Rehabilitation system is, in fact, one of the oldest and most successful case management systems known.

The Vocational Rehabilitation system is also very consistent from one state or one locality to another. This makes it possible to fund and utilize training, research, and demonstration centers which focus on specific populations across the country.

One problem that continues to surface in the system is having to deal with the overwhelming task of maintaining a knowledge base and manpower to serve all disabilities. This dilemma is usually handled by staff that "specialize" in a disability area, e.g., mental illness, or a particular skill, e.g., work evaluation. In-service training is also emphasized.

Another problem that results from attempting to serve all disabilities with inadequate levels of funding is the phenomenon referred to as "disability of the year." This critical quip refers to the movement of special demonstration, re-

search, training funds, and programs to a "popular" disability and then on to another before the first is adequately addressed.

However, the overall Vocational Rehabilitation system is one that Mental Health might profit from studying and emulating in many respects. Although Mental Health systems cannot count closures, they could improve management and accountability by counting services, costs, similar benefits, and dollars saved through service delivery.

Funding and Accountability in Mental Health

NIMH, 1985, delineates a succinct view of national expenditures and relevant factors which give an overview of dollars spent and expended for mental health services in the United States. They are as follows:

- During the 1980, total expenditures for mental health care in the United States were estimated to be between $19.4 billion and $24.1 billion.
- These expenditures represent approximately 7.7 percent of total expenditures for general health care and approximately 0.7 percent of the nation's Gross National Product (GNP).
- Of these expenditures, approximately 53.6 percent were incurred in the specialty mental health sector, 30.6 percent in the general health sector, and 15.8 percent in the human services and non-health sector.
- Nursing home costs were between 7.5 and 9.0 percent of total direct mental health care costs.
- Both the general health and the mental health care sectors expended a comparable proportion of resources on hospital-related care, and relatively fewer resources on drugs and sundries and non-hospital-related physician services.
- After factoring out inflation, the growth in direct costs of mental health care was about 1.7 percent yearly between 1977 and 1980, compared with an estimated growth in general health costs of 3.6 percent.
- Commercial insurance was the most frequently reported principal payment source for inpatient psychiatric admissions under age 65 to private psychiatric hospitals and nonpublic non-federal general hospitals. Commercial insurance and Medicaid were the expected principal payment sources for about equal percentages of admissions under age 65 to public and multiservice non-federal general hospitals.
- State mental health agencies directly controlled and administered more than $6.2 billion in 1981.
- Approximately $4.9 billion of the total revenues of state mental health agencies were derived from state government sources; approximately $0.8 billion from federal sources.
- On the average, state mental health agencies spent 66.5 percent of their budgets in state mental hospitals and 29.7 percent in community-based programs, but there was great variability across states.
- per capita expenditures across states ranged from a high of $66.74 to a low of $7.90, with a national average of $24.30.

"In 1980 we as a nation spent more than $30 billion dollars on psychiatric services; almost $20 billion of that could be considered public dollars, or money spent on public mental health programs. (Economic Fact, APA, 1983) The total sum represents 1.38 percent of our gross national product. But what did we spend it for? An antiquated, unresponsive, scandal-ridden mental health *nonsystem" (Talbott, 1985)*

> "As trite as it is to repeat an overworked cliche once again, it is still necessary to begin with the economic reality that over the last three decades' the money has not followed the patients'. It has not followed them from state hospitals into community mental health services of community residences or outside systems such as nursing homes and prisons, and it has certainly not followed them into the streets, where thousands of homeless mentally ill are currently living." (Talbott, 1985)

In the above excerpts, Dr. John Talbott, Past President of the American Psychiatric Association, articulates well the status of mental health systems. What appears is a system that is jerked around by numerous complicated funding resources with little ownership or accountability concerns for mental health program outcome.

For instance, in recent years treatment in private and general hospitals has risen dramatically due to Medicare and Medicaid reimbursement. Reimbursement schedules also favor treatment for the severely disabled in acute inpatient care, skewing services away from the community. Thus, the provision of community models can be out of reach for Mental health administrators and planners who believe in community services. (Ahr and Holcomb, 1985)

District CMHCs in Kentucky earn dollars for services delivered from over 30 different funding sources as well as various grants they compete to secure. It takes experience, genius, and creativity just to know where to go to find dollars, how to meet eligibility, how to write proposals, how to combine funds, and how to maintain a wide range of professional staff willing to work for "soft" dollars.

The National Association of State Mental Health Directors, 1984, pointed out that their number one barrier was financial discrimination against the long-term mentally ill. They specifically cited: A - Reimbursement policies in entitlement and insurance programs that exclude the mentally ill, restrict eligibility, or unrealistically limit coverage. B - Reimbursement policies that foster hospitalization. C - Absence of an eligible residential program reimbursement such as the ICF-M.R. for the developmentally disabled. D - Inappropriate restrictions in Title XIX reimbursement for the mentally ill who need specialized nursing home care. E - Competing and changing priorities that should have additional funding. (Example: youth, women alcoholics, etc.), but usually take funding away from the chronically mentally ill.

National efforts to curb medical costs through cutbacks in reimbursement, such as DRG's (diagnosis-related groups), further discriminate against those in need of comprehensive, long-term care. The competition of health service providers

encourages standard patterns of care that de-emphasize attention to individual needs which is crucial in working with long-term mental illness. The gradual withdrawal of federal dollars from a wide array of health and human service programs have also complicated the provision of services and supports for this population, with all these factors adding up to an inevitably explosive social and political disaster for our country.

Vocational Rehabilitation's Funding and Accountability

According to the National Center for Health Statistics, approximately 22 million individuals are disabled in such a way as to chronically limit their ability to function.

Recent polls conducted by Louis Harris and Associates found that one out of every three adults with disabilities are unemployed.

Congress has consistently recognized the Rehabilitation Program as the nation's responsible action to provide citizens with disabilities an opportunity to be a part of the mainstream as full participants. In fact, from 1980 to 1987 funding for the Rehabilitation Act, as amended, increased 65 percent while other human service programs faced budget reductions. Although Vocational Rehabilitation professionals support adequate funding for many programs which assist individuals with disabilities, the Rehabilitation Act commands top priority for their scrutiny and advocacy.

Having one comprehensive piece of legislation that is well-balanced and well understood is of unestimable value to the field of rehabilitation and the individuals it serves.

Comprehensive provisions include:

1. a comprehensive, individually-tailored program of vocational rehabilitation services designed to assist eligible persons with physical and/or mental disabilities to become employed;
2. a research program to develop new techniques in providing services;
3. a special projects program to target services to specific populations;
4. a comprehensive services program for independent living for persons too severely disabled to benefit from traditional vocational rehabilitation services;
5. a supported employment services program for individuals with severe disabilities not traditionally served by state vocational rehabilitation agencies or for those who have not traditionally been able to enter employment;
6. and other specially designed programs to reach new populations and test new innovative methods of service delivery.

This organization and simplicity allows all types of professionals, researchers, trainers, consumers, and families to target advocacy efforts effectively. Appropriations for fiscal year 1988 reached approximately $1,588,000,000. This is fewer dollars than the total spent on Mental Health programming, and yet ironically, Vocational Rehabilitation is usually thought by those in Mental health to have plenty of money. Perhaps this bias results from differences in management.

In spite of this solid funding, state vocational rehabilitation agencies are only able to serve approximately one out of every 20 individuals with disabilities who are eligible.

In addition, the size of this population continues to grow--through accidents, injuries, illnesses, and the occurrence of individuals disabled at birth--at an estimated rate of 500,000 annually. The rehabilitation dollar also continues to depreciate with inflation, resulting in fewer people served.

Rehabilitation services benefit our country's disabled individuals in intangible ways that contribute to quality of life as well as in tangible terms as tax revenues are increased for cities, states, and the federal government. The non-disabled population also benefits as the standard of living increases for all. Data have shown that the total investment in rehabilitation for any given fiscal year is totally paid back in four years, due to increased tax revenues and decreased dependency on government services. National Rehabilitation Association, 1988)

Professional Image: Our view of one Another

Individuals who are disabled, including those disabled through mental illness, have the right to be served by competent, professional staff who believe that each human being has the right to live as well as their abilities permit. They deserve accessible mature professionals who do their best to utilize other professionals and their programs as resources which contribute to their rehabilitation.

Although Mental health and Vocational Rehabilitation professionals usually intellectually agree that we currently have the skills to help persons with long-term mental illness obtain vocational independence through integrated community employment, little is actually done to work together in achieving this goal.

We must ask ourselves why it is so difficult at either a service or an administrative level, to cross this boundary and work cooperatively!

Many times we underestimate one another's abilities and look for the other's faults. There probably isn't a psychiatric rehabilitation counselor alive who hasn't been told that all a *primary therapists* wanted was for them to find their client a job. This request over-simplifies the knowledge and skill required in Vocational Rehabilitation services as well as the knowledge Mental Health could share concerning their expertise of the individual's particular disability and needs.

On the other hand, Vocational Rehabilitation professionals often express and share their frustrations by observing the Mental Health staff do not understand the demands of the marketplace or the support strategies essential to establishing a successful partnership with rehabilitation agencies and community businesses.

In a positive vein, Rehabilitation counselors and administrators agree on the suitability of CMHCs as the best locations for providing mental health services. However, they do not agree on the preferred professionals to deliver the services. Administrators select psychiatrists, psychologists, and social workers -- in that order -- whereas counselors name psychologists first, peer counselors second, and psychiatrists third. The counselors' strong preference for peer counselors

is matched by the opinion of consumer advocates. This is thought to reflect their self-help orientation and a degree of skepticism about professional interventions. (Thurer and Rogers, 1986)

Mental Health professionals express positive, although often mixed reviews of Rehabilitation's contributions. At a 1987 Symposium on Mental Health Administration, the view of Goldman and Morrissey, 1985, was discussed as follows: ". . . despite all its past and current problems with the establishment of sound training programs and meaningful professional standards, the profession that has done a long stretch of yeoman service in behalf of the most severely troubled has been rehabilitation counseling. Indeed, rehabilitation is the backbone of NIMH's Community Support Program."

Stephen White, a symposium presenter, continued to comment: "While I champion linkages between dissimilar professions and services, I see more similarities than differences between the four traditional mental health professions and broadly trained rehabilitation professionals. Although I know it will be a controversial proposal, I feel we must broaden our definition of "clinician" to include rehabilitation. By doing so we will at once justly recognize its past and current contributions and its legitimate role as part of an interdisciplinary team approach to treating mental illness and perhaps, in a collegial fashion, stimulate changes in their training and standards where some of us feel there may be deficits. (Administration in Mental Health, 1987)

[It is ironic that at this same conference, mental health administrators expressed their top inservice training priority as "Defining and defending the clinical domain as it intersects with other services." (Austin, Administration in Mental Health, 1987) This is exemplary of our mixed views. This appears even more self-defeating and illogical since this same group also cited a special study used as a baseline information for the conference which indicated that mental health administrators were spending a significant majority of their time at the boundaries between their organizations and others. The implications of this shift suggested that training programs for these administrators would now need to include such topics as negotiating, bargaining, public relations, brokering, facilitation of inter-organizational relationships, coalition building, contracting, conflict resolution, and systems analysis. (Mazade, Administration in Mental Health, 1987)]

When mental health and rehabilitation professionals are working cooperatively with a client, there needs to be a continual interchange of expectations as well as a mutual sharing of education, professional experiences, and insights so that their cooperative efforts will ultimately benefit the individual with whom they're working. Consequently, it is time for us to shed inconsistent, immature behavior that is self-defeating for both consumers and our own professions. We must cross the boundaries that are set up simply to define our mission -- cross them frequently and with ease.

Thurer and Rogers (1986) document that both rehabilitation counselors and administrators agreed that counselors demonstrate their greatest skills in vocational/career counseling and related personal/social counseling and have less skill in other needed areas. These administrators and counselors share the opinion that mental health services are best provided in community mental health centers (CMHC's), a view shared also by consumer advocates. This is important for several reasons. The national network of federally designated CMHCs can provide vocational rehabilitation agencies with linkages resulting from their many associations within a widespread, established organization. In addition, CMHCs are generally comprehensive in the arrays of services they offer and can often serve clients with limited financial resources.

Conversely, although some CMHCs are attempting to set up their own vocational programs, most realize that they must collaborate with vocational rehabilitation and utilize those resources in order to provide an adequate volume and quality of services for consumers.

Mental Health professionals must also understand that their clients may not initially be ready to participate in competitive employment at minimum wage or perhaps they cannot resume the same level of employment attained prior to disability. Likewise, vocational rehabilitation programs must not exploit clients' abilities to earn a fair wage in order to fulfill contracts or keep programs solvent. Both occurrences are destructive to all concerned.

Freud has been quoted as saying "work is man's closest tie to reality." Because this is proven to us again and again, we must work together to offer consumers the self-validating experience of using their time productively, be it paid or unpaid "work".

Why Work Together

The following outline delineates some of the more important advantages of a successful cooperative interagency agreement for rehabilitating persons with mental disabilities.

For the Mental Health Agency:

- Increased services to a priority population, the long-term mentally ill, which is currently underserved.
- Increased patient services without addition of staff or increased costs.
- Provision of vocational assessment, counseling, training, placement and other services for mental health consumers.
- Provision of re-training and placement for persons whose disability prevents them from remaining in their regular occupation or employment.
- Assists mental health consumers in staying in the community. (The majority of mental health consumers are now in the community and this increases the possibility of rehabilitation.)
- Reduces incidence of hospitalizations, and therefore, significantly saves dollars.
- Vocational Rehabilitation may provide payment for some selected services when negotiated in the agreement. This relieves some of the economic burden for patients who are self-pay and for overextended mental health program funds.
- Vocational Rehabilitation may sometimes provide specialized medical evaluation and care for physical problems which may be contributing

to, complicating, or even causing the mental disability.

- More Vocational Rehabilitation services are available to Mental Health clients (Rehabilitation agencies select about one (1) client out of every 20 eligible referrals.)
- Raises the total quality of care in the mental health program and assists in meeting various standards for quality care, e.g., J.C.A.H.
- Encourages consultation and moral support between agencies.
- Encourages closer relationships with business and industry by extending services into the world of work.
- Encourages a good public program image through the visibility of patients who work and contribute to the families and communities.
- Increases mental health advocacy and the leverage to influence legislation and funding for citizens with mental disabilities and consequently for the mental health profession.

For the Vocational Rehabilitation Agency:

- The Rehabilitation Agency can benefit by accessing similar benefits for their clients. (In Kentucky community mental health programs receive payment for services from over 30 different sources and all of these services and funds are available to eligible mental health/rehabilitation clients under the cooperative program.) This literally expands the Rehabilitation budget by thousands of dollars.
- Mental Health referrals are more likely to be severely disabled and documentation of the disability is usually readily available without cost to the Rehabilitation Agency. This increases the percentage of severely disabled closures for rehabilitation at the local, state, and national levels.
- Mental health referrals take no more time than the average rehabilitation client and cost less per case than the average rehabilitation. This increases the number of closures possible for a rehabilitation agency within the same available budget.
- Expertise in psychiatric rehabilitation and readily available mental health consultation increases the effectiveness of the entire rehabilitation agency in working with **all disabilities**. One person in every six or seven persons in the general population needs mental health care in their lifetime and the incidence is even higher for those physically disabled individuals who are under even greater stress. Therefore, a rehabilitation agency **cannot** conceivably avoid working with persons who have mental disabilities and expertise in this area is essential.
- Mental disabilities constitute a large percentage of our disabled community, and since no easy or certain cure is available, a large community of these disabled individuals are in need of rehabilitation. This disability is increasing in incidence yet it has considerable potential for successful rehabilitation. Therefore, this is fertile ground for rehabilitation agencies to seek referrals which will yield cost-effective rehabilitations of severely disabled individuals.
- A Cooperative Program raises the quality of services and the accountability of the rehabilitation program.
- Encourages consultation and moral support between agencies.
- Encourages closer relationships with business and industry through linkages with services that address mental health, mental retardation, and substance abuse services for troubled employees and/or their families.
- Encourages a good public image of the rehabilitation agency which can deal with a wide range of disabilities.
- Increases advocacy and the leverage to influence legislation and funding for the disabled community and consequently for the rehabilitation profession.

For Consumers and Families:

- Increased economic self-sufficiency.
- Greater diversification of job training and employment options.
- Greater opportunity to work in normal business settings within the community.
- Increased opportunities for socialization with persons who are both disabled and non-disabled.
- Heightened community awareness of the work and productivity possible for persons with severe disabilities.
- The financial ability to secure more adequate food, clothing, and housing.
- A more self-efficient society.

The only way to develop a successful cooperative program is for the mental health agency and the rehabilitation agency to confer and to negotiate a cooperative agreement which emphasizes positive working relationships. There must be representation from all levels (federal, state, and local) of each agency in order to draft a realistic working agreement and all levels must be aware of the agreements provisions and pledge themselves to abide by its terms.

A cooperative agreement should facilitate the following work:

- Give each agency the authority and direction to do work together.
- Identify the service needs and priority populations to be served.
- Establish referral procedures and state eligibility criteria which reflects that established in the Rehabilitation Act.
- Define an acceptable and legal method of exchanging confidential information.
- Define overall program funding and payment for specific services (including information on

eligibility and timelines for payment).

- Set agency goals that are to be mutually achieved.
- Address continuity of care and/or services.
- Provide for joint training and education.
- Establish procedures for resolving any conflicts or disagreements.
- Define guidelines and set dates for renegotiation of the agreement (plan to make the agreement more realistic and tailored to agency needs at that time).
- Specify how the agreement can be terminated, if necessary, by either party.

Once the agreement is in place, cooperative work must be approached as a positive learning experience wherein each part expects to grow, show flexibility and respect for one another. This road can and has led to an extremely productive relationship for mental health and rehabilitation agencies, but more importantly, it can and has led to increasing rehabilitation opportunities for citizens with mental disabilities.

Summary

It was recently my privilege to attend a Community Support Conference convened for 15 states where I spotted a consumer I have known for several years who remains active and vocal on issues. He has recently begun to travel throughout the country to such events pushing his own, empty wheelchair.

At first glance, I was amused, then bewildered. Giving this image more thought while driving home, I was struck beyond words with the symbolism. Perhaps those working in any area of psychiatric rehabilitation will understand why.

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Excerpts of Reviews & Comments

The following are excerpts of reviews, comments and recommendations made by the 1988 Switzer Scholars. These are presented to further stimulate thinking, discussion and action as they relate to the content of "The Coordination of Efforts Between Vocational Rehabilitation and Mental Health Systems" by Joan T. Barker, CRC.

Joan Barker has given us an overview of the parallel changes that have occurred during the past couple of decades as they relate to vocational rehabilitation and mental health services to the most seriously mentally ill. She seems optimistic that trends have been moving toward increasing coordination of joint efforts and that the 21st century therefore looks brighter for vocational rehabilitation of this seriously disabled and stigmatized group of people.

I am inclined to be optimistic, too, but I am not nearly so sure about the pace at which this positive outcome will develop.

During these past decades I have had quite a number of opportunities to cross the boundaries between mental health and vocational rehabilitation and to shepherd and direct conjoint and collaborative programs. I have brokered joint agreements between state agencies in the two fields and, under the auspices of the NIMH Staff College and more recently through one of the R&T Centers, have directed and taught seminars for staff from both settings. There is still a lot of work to be done before there is any real collaboration in sight that can have positive results for the population both express concern for.

Just to list some of the obstacles remaining to be tackled will illustrate my lack of sanguineness:

1. There is still abysmal misunderstanding by each agency staff of what are the other agency's mandates, resources, and limitations.

2. This has lead to disparate definitions of many common terms, e.g. "work", "employment", "therapeutic", "remuneration", "subsidies", "support."

3. Without clarity as to the other's mandates and resources each service provider becomes convinced that there is "creaming" of clientele, of power plays through funding control, and much else.

4. The changing understanding of what is chronicity in mental illness, what is eligibility for psychiatric services and what for vocational rehabilitation, presents difficulties for collaboration.

Nevertheless, the advantages of collaboration far outweigh any dangers. Rehabilitation of any kind takes teamwork, more so for mental illness. Collaboration between the mental health and VR agencies is a significant step toward ensuring the teamwork necessary to successful outcome.

The newer developments in both human service spheres (e.g. better uses of medication, multiple family therapies, self-help advocacies, on the one hand; supportive work, on the other) call for collaboration. Change comes slowly!

-Bertram J. Black

Joan Barker's paper is an extensive and detailed summary of the multitude of issues, barriers and opportunities represented in the growing network of relationships between the mental health field and the world of work.

In the historical overview of both the mental health and vocational rehabilitation fields, the paper contains much interesting background which serves to explain the profound difference in "world view" of practitioners in each of these fields, as well as some of the practical barriers to collaboration. In fact, the format of the paper, which alternates between discussions of the same topic from the perspective of each of the two fields, is clear commentary on how little the two fields have evolved a sophisticated and effective set of working relationships. It is indeed interesting that after over a decade of calls from each level of government for stronger collaboration between mental health and vocational rehabilitation, the final section of the paper still needs to present a rationale for this collaboration titled "Why Work Together?".

The paper might have been strengthened by:

1. focusing on the larger issue of psychiatric disability and the world of work. Not only is there a great deal of activity in this broader area nationally that does not involve vocational rehabilitation, but our thinking as a field in this area is undergoing major change, particularly as it relates to fundamental assumptions about the potential of people with psychiatric disability to lead more productive lives. In fact, a dismal view of people's potential seems to be a common assumption of mental health and vocational rehabilitations staff in many current service systems.

2. including examples at both a systems and a program level where vocational rehabilitation and mental health are actually working together well.

3. presenting an agenda which we need to pursue for the future. If the differences between the fields, for example, are so pervasive, and if attempts at collaboration have been so unsuccessful, perhaps we should consider either abandoning efforts to "collaborate" at either state or local levels, and turn to other sources of jobs (e.g. rehabilitation practitioners in mental health working directly with employers), at the same time as we turn up the political heat on rehabilitation agencies at the federal and state levels to stop discrimination against people with mental illnesses.

4. acknowledging the substantial developments within the field of mental health to assist people with their rehabilitation. Program models such as Fountain House, practitioner technologies such as that disseminated by the Center for Psychiatric Rehabilitation, are all much more sophisticated responses to people's employment needs than developments we have seen within the field of vocational rehabilitation. They can be used as tools to more clearly and pragmatically describe

which pats of the rehabilitation process we (mental health) should be focusing on, and which parts vocational rehabilitation should be responsible for. But this is only possible if we have a sense of shared mission, common values and assumptions about people with psychiatric disabilities, and a political mandate to work together on relatively clearly defined outcomes, such as jobs or other productive activities which reflect the aspirations and skills of individuals with psychiatric disabilities.

-Paul J. Carling

The creation of the Community Mental Health Centers (CMHCs) has had an impact on the provision of services to persons with psychiatric disabilities. However, I am not sure that the impact is all positive. Persons with chronic disabilities do not always receive the services needed because funding for specific services must be approved. If the person is not considered eligible for vocational rehabilitation services due to the chronicity of the illness and he does not get services from the Mental Health system, where does this person wind up? The answers are: 1. in an overprotected home environment; 2. in prison; or 3. in substandard housing living on a fixed income.

To prevent this from happening, effective teamwork must take place. Unfortunately, "turf" becomes a problem. Efforts should be made to eliminate or, at least, minimize squabbling among professionals. Joint training sessions and regular monthly meetings between CMHC and VR professionals will help.

Chronicity of illness tends to burn out not only clients, but professionals in the field as well. Efforts must be made to minimize "burnout".

Studies show that anywhere between 70-80 percent of the people sentenced to prison are sent for drug related offenses. An all out campaign must be started, not only from a preventive standpoint, but also to provide adequate services to people while in prison.

-Robert J. Neuman

The underlying premise of Barker's article is that although barriers exist between mental health and vocational rehabilitation which complicate and discourage their working relationship, there are numerous advantages for these two professions to work cooperatively. First, the author gives an overview of the differences of the two professions in such areas as history, mission, funding, organizational structures and legislation, and second, she outlines the benefits of the two systems working together in rehabilitation of mentally ill persons. Then lastly, she delineates the necessary components of a successful cooperative working agreement for the two professions.

This reviewer was enlightened as to the widespread existence of the problem of mental health and vocational rehabilitation systems working together. Barker maintains a rather upbeat perspective on finding solutions to this very serious and difficult problem.

From the perspective of a mental health professional, it appears that the principles inherent in the provision of psychosocial rehabilitation services frequently cannot be adhered to in the constrictive and rigid perimeters that govern many vocational training programs. Such perimeters include time limited training programs and case termination of place clients. Current supported employment initiatives within vocational rehabilitation are now more similar to transitional employment models within psychosocial rehabilitation. These models can better serve mentally ill persons by compensating for the problem of timely and daily attendance to a job. Therefore, innovative programs in supported employment should be encouraged. In addition, vocational rehabilitation policies need to address the issue regarding the concept of providing continuing, not time limited, services to maintain people with mental illness in the community. These services, in fact, may be life long, particularly for those with long-term mental illness.

Education needs to be provided to both mental health and vocational rehabilitation professionals in certain highly sensitive areas. First, for mental health providers, they need to become more realistic in understanding what vocational rehabilitation workers can actually offer their clients. In turn, vocational rehabilitation providers need to understand the philosophy and programs of psychosocial rehabilitation and to overcome their own stigmatization of people with mental illness.

-Carole Schauer

Rehabilitation & Mental Health Systems Working Together

Summary of Recommendations

The following is a summary of the recommendations for action developed by the 1988 Switzer Scholars as they relate to "Coordination of Efforts Between Vocational Rehabilitation and Mental Health Systems" by Joan T. Barker

I. Recommendations to Enhance Service Delivery:

1. That rehabilitation processes in the mental health system utilize team approaches, with consumer and vocational rehabilitation counselor always being members of the team. The added costs involved could be shared between the vocational and mental health agencies.

2. Increased attention should be paid to young people, dually diagnosed as mentally ill and substance abusers. Modify regulations and other language which specifies there be freedom from drugs before services can be offered. Experience has shown that such a precondition is rarely possible.

II. Recommendations for Policy and Program Development:

1. The Social Security Administration should be stimulated to simplify procedures for obtaining and maintaining coverage, and that these be related to rehabilitation goals.

2. Concern should be stimulated for persons with mental illness caught in the criminal justice system.

3. Preparation of collaborative agreements is urged between vocational rehabilitation and mental health agencies in all states, and these should be prepared by authorities in a position to carry them out.

4. An emphasis on greater concern is urged for those persons physically disabled who also have mental problems.

5. Attention should be focused on persons with a mental illness and how to enable them to continue to function on a job. Perhaps increased knowledge will accrue from experiences with "supported work."

6. There is a need to strive for a common (perhaps generic) definition of **rehabilitation**, understandable to both the vocational rehabilitation and mental health fields. We must deal with current definitions and interpretations that vacillate between calling rehabilitation some form of treatment, on the one hand, and calling it simply a form of general social welfare, on the other.

III. Recommendations for Training:

1. It was recommended that the mental health field recognize that Vocational Rehabilitation Counseling is a distinct professional discipline applicable to services to mentally ill persons. It was felt that the Rehabilitation Services Administration, the National Institute of Mental Health, the National Institute of Disability Rehabilitation and Research, and the various states should assist in increasing the opportunities for training in that discipline.

2. In-service training across various disciplines should be carried as a responsibility by one field to the other. In addition to the human service fields, the social sciences should be included.

3. In the training of professionals to be engaged in rehabilitation practice, there should be greater attention to training in the skills of such administrative practices as organization, planning, and policy-making.

IV. Recommendations for Research:

1. There is a great need for longitudinal data, particularly the need for outcome information over time.

2. The following facts need to be known: who goes onto benefits and what happens to them; who is helped with vocational choices and whether vocations result; and to what extent do persons serviced through vocational rehabilitation achieve productive participation in society.

3. Better cost-benefit studies are needed that go beyond the simple "costs versus earnings and taxes paid" analyses.

4. Monitor the results of social welfare legislation, including the statutes affecting persons disabled, but working, and the new social services ("workfare") laws. What are the effects on persons with severe mental illness?

5. Study what the effects of the population changes now taking place will be in the next decade, particularly the projections of persons with mental illness.

V. Recommendations for Legislation:

1. There should be careful consideration, shared by those with vocational rehabilitation and mental health expertise, of problems with current legislation (e.g., the 20 hours per week restrictions in the Social Security "gainful employment" and rehabilitation transitional work regulations).

2. Review provisions for mental health insurance and the development of more equitable legislation for coverage of this target population.

3. There should be legislation that provides for the systematic combining of funding sources to enhance the management and coordination of programs for persons with long-term mental illness.

The Role of the Consumer Movement and Persons with Mental Illness

Esso Leete

I am a person, an individual, a human being. I happen to have schizophrenia. For over 20 years I have lived with and in spite of it, struggling to come to terms with my illness without giving in to it. Although I have fought a daily battle, it is only now that I have some sense of confidence that I will survive my ordeal. Before I describe what the consumer movement has done for me and others, and what we in turn have contributed to others like us and to the current mental health system, let me give you some background on myself, my history, if you will. It is not an unusual story.

I am the eldest of three children. My father was in the Army and we moved every few years, including to Germany. I was shy and slow to make friends, and these frequent uprootings were extremely difficult for me. I sorely missed the predictable routines, stable friendships, consistent schools, and familiar house that others enjoyed.

We returned to the United States for my senior year of high school, which is when I became ill. I didn't know it at the time (and I think others denied it), but looking back I can see the changes. Except for participation in sports I had always been more comfortable by myself, and in my senior year I became increasingly withdrawn and sullen. I felt alienated and lonely. Everyone was so distant from me: there seemed to be a huge gap between me and the rest of the world, including my family. I watched dispassionately as my two younger sisters matured, dated, shopped and shaped their lives, while I seemed stuck in a totally different dimension.

I graduated as a National Honor Society member from high school. It was expected that I would get a scholarship and I did. When I reluctantly went off to college, however, I was without my family for the first time and totally unprepared for life away from home. Although I was able to perform my school work, I remained isolative; I had no close friends and as time went on, I spoke to virtually no one. I found myself drawing pictures of Van Gogh and writing poetry in classes instead of taking notes. I saw myself in a foreign world that I could not always translate. At one point I believed I was on Venus. I forgot to eat and began sleeping in my clothes. Even routine things like taking a shower rarely occurred to me.

Towards the end of the first semester I had my initial acute psychotic episode. At the time I did not understand what was happening and it was extremely frightening. One night while walking alone on a beach my perceptions suddenly shifted. The intensifying wind became an omen of something terrible, trees and bushes bent threateningly towards me, and tumbleweeds chased me. I was running but making no progress. When I finally reached my dormitory after what seemed like hours, I was exhausted, confused, and hearing voices for the first time. Later that week I had other similar experiences, still not comprehending that I was out of touch with reality as others knew it. That reality had given way to the multiple realities with which I would now live.

Esso Leete is the president of the Consumer-Centered Services in Colorado.

One day soon thereafter I returned from classes and was surprised to find my father in my dormitory room, my bags packed and waiting at the door. Someone must have notified him of my condition, for he had come to take me away. He had been advised that I was ill and should be treated in a hospital; this was my first psychiatric admission. Diagnosis: Schizophrenia. Prognosis: Extremely guarded. I was treated with medications and released after a few months. I have since been hospitalized 15 times, the longest hospitalization lasting a year. I have had twice as many doctors. I have had 10 different diagnoses (most of them variants of schizophrenia), have been prescribed nearly 20 medications, and had almost every kind of therapy imaginable, including seclusion and 4-point restraint "therapy," as well as insulin coma therapy concomitant with E.C.T. (electroshock). In other words, I have been treated with everything for everything. Yet I have survived.

Self-Help and Advocacy Efforts

I owe my survival in large part to the consumer movement and its advocacy on behalf of the mentally ill. For, unlike what we so often hear, most of us are able to speak for ourselves and to represent our own needs. We are doing this more and more, and others are finally listening. Mental health clients are now making choices both individually and collectively, and we are controlling our own lives. We are becoming empowered.

The consumer movement in mental health, which has been a long time coming, is primarily one of self-help. Although Clifford Beers' book "A Mind That Found Itself" may have been instrumental in terms of expressing and validating a patient's perspective, it did not at the time result in widespread consumer empowerment. Indeed, the organization that he founded has become the National Mental Health Association (and its branches), a group "for patients" but certainly not by them. Unfortunately, this has typically been the case, with mental patients being seen as too sick and incompetent to speak on our own behalf, certainly too disorganized to band together for any purpose, even our own self-preservation.

Yet there has been in this country a widespread realization that self-help techniques are extremely beneficial. We have seen the development and success of Alcoholics Anonymous, the Association for Retarded Citizens, Mothers Against Drunk Driving, and the National Alliance for the Mentally Ill (a group of family members), to name just a few. And, of course, we have Ralph Nader's influential group, which I feel has done much to validate the right of consumers to hold providers of all types accountable for the quality of their services. These and other groups representing consumerism have become extremely powerful lobbying bodies due to the staggering numbers of individuals represented in their ranks. Considering the huge population and potential pool of current and former psychiatric patients, one begins to realize the immense impact our consumer groups can have.

There has been a dramatic increase over the last 10 to 15 years in advocacy by and on behalf of the mentally ill. Yet with the exception of Recovery, Inc., most of our own truly representative groups have begun only recently. We now have two national patient organizations, one moderate in stance (The National Mental Health Consumers' Association) and one more radical (The National Alliance of Mental Patients), in addition to many regional groups. The National Alliance for the Mentally Ill has established the Client Council, a committee formed under NA.M.I. to consult with them on consumer issues, although significant progress has been admittedly slow.

There are also monthly client teleconferences, annual national consumer conferences (the largest being "Alternatives"), state and local meetings, a Protection and Advocacy system, client newsletters, hotlines, peer-run mutual support groups, and some involvement with class-action lawsuits geared towards demonstrating and changing patterns of poor care and inadequate mental health services.

The Effects of Stigma

For most of these consumer groups, the goal is to change the existing mental health system, to make it more responsive to us and thus more effective. Unfortunately, in many places we are still fighting for basic civil rights for mental patients and an end to victimization. We are demanding such basic rights as employment (at equal pay), insurance coverage, and housing. Many states still do not have laws against openly discriminating against persons with mental illness, and as a group ours is possibly the most discriminated against and disenfranchised. We are therefore organizing to stop unjust and oppressive treatment, to have a voice in our own treatment, to gain mastery over our lives, and to lend much-needed support to each other as we do this.

Fortunately, physical abuse and neglect of mental patients is no longer rampant. Instead, however, we are now faced with a less visible but no less brutalizing psychic cruelty: stigma. It has been my experience that there is nothing more devastating, discrediting, and disabling to an individual recovering from mental illness than stigma, which Webster's (in an archaic edition) defines as "the scar or brand left by a hot iron on the face of an evildoer." This in itself says much about the enormity of the task before the mental health consumer movement, because we are still seen by some as evil (even possessed) and indeed our psychiatric history remains with us quite tenaciously.

In addition to psychological handicaps imposed by our illness, the mentally disabled must constantly deal with this stigma and other obstacles to empowerment and recovery erected by society. We are seen as unattractive, lazy, incompetent, unpredictable and dangerous. Although these are untrue stereotypes, admittedly we do have shortcomings. In many cases, however, our weakest attributes are those we learn in the very institutions supposedly there to help us: i.e., withdrawal, dependency, fear, irresponsibility, and lowered self-confidence, lost self-esteem, and shattered personal dignity. In fact, just the label "mentally ill" is powerful enough to cause changes in our behavior and functioning.

To make matters worse, fears and misconceptions surrounding mental illness are heightened by the media. For example, research has found that 70 percent of all television characters labeled as mentally ill are violent, which, of course, has absolutely no basis in truth. Unfortunately, we rarely read about people who have successfully dealt with their emotion-

al problems and are making it, and they will not usually identify themselves because they are all too aware of society's general attitude.

The current image the public has of the mentally ill must be changed, not to mention that of the individual himself, who has grown up in the same society and has incorporated those negative attitudes about mental illness, yet is himself forced to live with the label. This is the stigma within, our greatest enemy and the biggest threat to our recovery. We must defeat this internal stigma if we are to be effective in making changes to our lives, including our psychiatric care. The consumer movement by its very existence serves to assist us with this difficult task.

Indeed, life with a diagnosis is difficult. I can talk but I may not be heard. I can make suggestions but they may not be taken seriously. I can voice my thoughts but they may be seen as delusions. I can recite experiences but they may be interpreted as fantasies. To be a patient or even an ex-client is to be discounted. Your label is a reality that never leaves you; it gradually shapes an identity that is hard to shed.

It is imperative for us to force ourselves out of the straitjacket of society's misconceptions. For until we eliminate this stigma, we will have prejudice, which will inevitably be expressed in terms of discrimination against persons with mental illness. In addition, stigma stifles the development of a positive self-image that would assist in the rebuilding of our selves, thus limiting our involvement in the consumer movement.

Patient-Controlled Alternatives

One of the first ways that mental health consumers became active in their own movement and on their own behalf was by establishing local client support and advocacy groups. I have found that one of the best ways to improve my self-image, receive the support I need, and find hope for the future is by participating in a peer-run mutual support group. In a self-help group, members are uniquely both service recipients and providers, a role for which we are well-suited, and this contributes to the success of the group.

We as primary consumers need to meet socially with others who have experienced what we have, to exchange information about coping skills, and to take responsibility for ourselves. We must meet with others like us in order to see firsthand what we have accomplished and what we can achieve, drawing strength and hope from each other in this way. I have seen that our stigma can be vanquished in such a mutually-supportive atmosphere, where each member is accepted and affirmed, valued and validated. And we can accomplish this with pride, in a group founded by us, shared equally among us, sustained by us, and enriched by us.

As previously mentioned, there are other forms that the mental health consumer movement has taken as well. And although there do exist two different national patient groups with sometimes differing philosophies about treatment, there are nevertheless important similarities. In fact, the patient movement as a whole shares much in terms of attitudes towards support, advocacy, and empowerment.

Patient-controlled alternatives to the traditional mental health system are becoming more prevalent because they utilize clients in their conceptualization, implementation, and evaluation. This has been extremely effective in terms of service provision; it is always preferable to offer services based on your own personal experiences as an ex-patient and on what the recipient identifies as his needs (which the traditional mental health system often seems unwilling to hear), a background missing in current mental health providers.

Consumer-run alternatives like these form because there is a definite need. The mental health consumer movement is meeting this need for us. We have found that visiting a mental health center is not enough, taking medication is not enough, being loved by your family is not enough. There are benefits that only a group of your peers can provide: the opportunity for non-threatening reality-testing in a non-hierarchical group of your equals, peer group modeling with mutual feedback and problem-solving, and unconditional social acceptance with truly emphatic understanding.

Increasingly, alternatives to traditional therapy such as support groups and drop-in centers include no therapist, no mental health professional; assistance is provided by and to primary consumers. Decisions are made by the clients. Services are free to everyone; participation is not based on health insurance coverage. There is no requirement to attend; presence is completely voluntary. By choosing to participate in these client activities, we have been able to take more control over our lives, and we naturally feel both a sense of ownership and empowerment.

Any form of consumer gathering has a non-competitive, cooperative orientation and an anti-bureaucratic focus. Contact is usually informal and non-threatening. We define our own needs. The emphasis is on information shared "from inside," by others who have experiences similar to our own, not dispensed by professionals distanced by their own ignorance and biases. We treat each other with respect and tolerance, thus affirming our identity as individuals and endowing us with a sense of self-worth and inner strength. We share a genuine interest in helping others with their problems, and we validate each other. There is a focus on taking control of one's own life and strong optimism regarding ability to make these changes.

In such a group of fellow consumers we feel a real sense of belonging, in sharp contrast to the isolation with which we are all too familiar. Here we develop helping skills, a sense of cooperation, and feelings of competence and control, thereby liberating our minds from dehumanizing stereotypes we have learned to internalize. We have seen that we are one in the struggle, the pain, the disappointments, and that we can also share the dreams, the aspirations, and the triumphs of our peers. And more and more, mental health clients are realizing the power we have and the difference we can make in improving the lives of others labeled mentally ill.

Yet there remain definite obstacles to accomplishing this task. Our right to make decisions is ignored because society has given over control of our lives to hospitals, professionals, guardians, and the court system. It is obvious that others feel we are incompetent to make decisions for ourselves, much less become peer providers and advocates. They are fearful and distrustful of us. Power struggles escalate as professionals sense that they are in competition with us for control (as they are) and as their image, identity, and roles are questioned and threatened. We also sometimes clash with family members,

because although they may be genuinely trying to help us they have never been us. Clearly, consumer empowerment is frightening to many of these people.

Regardless of opposition, we must continue these efforts on our own behalf. Mental health consumers are now uniting and speaking with a unified voice, thereby becoming more self-sufficient and independent. Consumers are relying on other clients for information nd support, realizing that in many ways a personal experiential knowledge is more valuable than the education of professionals. To this end, as mentioned previously, valuable information is shared in monthly teleconferences, with consumer representation from many states. This is extremely useful because it links individuals with others to dialogue about new ideas for consumer-run programs, to receive feedback and additional insights, and to network with many different individuals and groups with whom they would not otherwise have had immediate access.

Legislation is discussed and support often given or withheld. The group responds to trends in mental health care, many of which are frightening to us because they are seen as limiting our freedoms. Information is exchanged regarding grants and other opportunities for mental health consumer organizations to begin or expand. It should be noted that we are frequently denied access to this information because mental health agencies are reluctant to provide it to us. This is a deplorable state of affairs and one which activist groups are working diligently to change.

There are now many client newsletters which perform similar functions. In addition, peer-run support groups and consumer-run drop-in centers are being established. These are significant especially because ex-patients serve as providers of services, drawing on their vast repertoire of personal experiences. This has been successful because many individuals who have had negative results from the traditional mental health system, and therefore avoid it, have been willing to meet with clients like themselves to receive services. Because these peer-providers speak from first-hand experience and involve the clients much more directly in this process, opposition is at a minimum, and therapeutic services can be given to these individuals often labeled as "treatment-resistant."

There is also a National Mental Health Consumer Self-Help Clearinghouse which gives technical assistance on a variety of issues. Information is provided, for example, on how to start a self-help group, fund-raising, public relations, advocacy, and networking. Consumer-run businesses are also being formed, where clients work in their own businesses to provide services. Sometimes we are consultants to other business ventures, most notably mental health programs. An example of this situation exists in Denver, where individuals identified as "chronic mentally ill" have been trained and then hired as Case Management Aides at the mental health centers, using their expertise to assist other clients with tasks such as finding housing, obtaining entitlement benefits, locating jobs, etc. Not surprisingly to me, this has been an extremely successful program, and these consumer providers are currently in the process of incorporating their own business.

Major Issues for Consumers

Most of us with a psychiatric history are searching for a healthy identity; we are struggling with what term to use for ourselves. Are we mental health patients, consumers, primary consumers, clients, ex-patients, inmates, survivors, or persons who have been psychiatrically labeled? The problem is complicated because everyone has his own individual connotations regarding these terms. Obviously, this situation involves semantics and has significant repercussions for us due to both our own self-image and the ways we feel stigmatized by our labels in the community.

There is also concern because of confusion by the public regarding the term "consumer." Because some people, most notably N.A.M.I. members, also refer to family members as "consumers," we have tried to make the critical distinction between what we term "primary" and "secondary" consumers -- patients and family members, respectively. This has come to be an important clarification; for example, there have been times when our interests have been represented by family members due to ambiguity in board membership criteria. Primary mental health consumers take exception to this. We feel we should represent ourselves and our own interests, while family members continue to stand for theirs.

Presently there are several issues on which the mental health consumer movement is working. Although there may be disagreements between the two national patient groups on some of these, it is significant that clients now have a choice of groups based on our viewpoints on these issues. Most fundamentally, there is the question of the right to refuse treatment versus the right to treatment, hopefully humane individualized treatment that works to meet our own identified needs and in which we can participate.

The administration of medications to patients involuntarily is currently a much-debated topic, both among consumers and among physicians, family members, and attorneys. The involuntary commitment process and outpatient commitment (usually requiring an individual to take medication or receive regular therapy) are other areas of dispute, with advocates favoring broader commitment criteria and easier admission into psychiatric facilities. There is also concern over the use and/or overuse of E.C.T. (electroconvulsive therapy). Advocates contend that it is useful in cases of extreme and non-responsive depression, while opponents assert vehemently that it causes brain damage, most notably evidenced by loss of memory and diminished capacity for learning new information.

What is important here is that as a result of the consumer movement in mental health, we are finally becoming involved in these issues which affect us so directly. Because we are networking with other clients, our ever-growing movement is now a force with which to be reckoned. Clients are demanding a choice and a voice. Although many of us do serve on mental health boards and committees, all too often we are still being placed on these bodies as mere token consumers, and consequently we do not have as much impact as we might. For this reason we must work harder to achieve representation by more than just one individual (who runs the risk of being ig-

nored, intimidated, or otherwise rendered ineffective). There is too much at stake to be satisfied with this situation.

In addition, it seems clear that we need to push for affirmative action as it relates to the mentally ill. We are definitely a minority, a sub-population that remains grossly ignored, discounted, and disenfranchised. Many of us will need the boost of affirmative action to overcome the societal disadvantages we face, as well as the handicaps we experience from our illnesses.

Problems with the Current Mental Health System

There are changes that can be made now in the delivery of mental health services that will ensure a quality life in the community for those of us afflicted with a major mental illness. The goal of these modifications should be the achievement of our highest degree of independence and productivity. As we attempt to deliver effective services to individuals with severe and persistent disabilities, there are certain service system principles which should be borne in mind. Most importantly, services should be consumer-driven and designed to be responsive to client needs in order to be effective.

It is important to offer a coordinated continuum of comprehensive services, a broad package of services offering emotional, financial, and community support. Our needs are far-ranging and include such things as food, housing, social services, case management, medical care and medication management, psychotherapy, crisis intervention, legal protection, education and vocational training, employment, and recreation. Community treatment programs must assume responsibility for helping us acquire these resources. A comprehensive case management system could assist us in understanding the system, finding out what services are offered and where, establishing our eligibility, and helping us maneuver through the necessary paperwork. As a part of this, we need adequate discharge planning and aftercare.

Currently there is little communication and coordination between agencies, even less between levels of government, so that acceptance of responsibility is often absent. There are many different agencies involved in service delivery to the mentally ill, most of which have no comprehensive understanding of resources available, and these various bodies are reluctant to work together to supply these services when and where they are needed. Not surprisingly, the lack of a mechanism ensuring continuity of care between providers has resulted in very little among these treatment agencies.

A good example is the frequent lack of cooperation and coordination between entities working with the special populations of dually-diagnosed, either with both mental illness and developmental disability or with both mental illness and substance abuse, a widespread problem of crisis proportions. Few professionals have been specifically trained to treat patients with two diagnoses and therefore few programs have been designed to perform this function. In addition, there are sub-populations such as the elderly, hearing-impaired, or those inappropriately incarcerated whose needs are not being adequately met due to insufficient specialized services.

Confusion also arises because many persons with mental illness may be transient, homeless, or for some other reason choose to attend a program which may not be open to them. Client choice is an important aspect of recovery, and we should be able to choose the program we wish to attend. Yet this does not happen. Even if personnel at the mental health centers do have some knowledge about what services exist system-wide, they are reluctant to make referrals based on politics and a misguided sense of loyalty to their agency. These considerations often take precedence over the best interests of the consumer.

We must establish an integrated human services delivery system in which providers work together cooperatively instead of avoiding responsibility and shifting patients around because they do not want to work with us. We are denied timely appointments, kept waiting in mental health center lobbies or hospital emergency rooms indefinitely, and our phone calls are not returned. If we are fortunate enough to get in to see a doctor, our visit is usually limited to 15 minutes to discuss medications. If we are given a therapist, the therapeutic relationship and alliance is shattered by routine staff turnover, and we may wait months to be "assigned" a new therapist. This does not result in our improved mental health, but instead leaves us feeling unwanted, discounted, and devalued.

It will be necessary to design a new system in which the dollar follows the patient and we receive the services we need. We must establish a flexible system designed to adjust to the fluctuating needs of the mentally ill and services must be racially and culturally relevant to be effective. Obviously, it will be important to document the effectiveness of working together and continuity of care from a cost-effective standpoint as well as its clinical usefulness. We must ensure that those mental health centers or other service systems which provide the most beneficial treatment are rewarded financially. As with other businesses, in the end competition will hopefully ensure that the best services are provided.

Treatment should be carried out in the least restrictive environment possible. The treatment program must be individualized and flexible, focusing on strengths and working with these assets to meet needs and develop positive self-esteem. Techniques for stress management and problem-solving should be taught to assist with our task of living with a chronic illness. This may be maximally effective if done in a classroom setting, where we are "students" instead of reinforcing our sick role of "mental patients." I think this format also ensures that this task will be taken seriously, fostering more complete learning. We should be assisted to recognize and use the natural supports that exist in our community. Many of us require guidance in using public transportation, cooking, and budgeting money, and suggestions and encouragement from family members can be extremely useful.

Motivation to persevere and remain involved with life is often difficult to sustain. It is easily eroded as we experience intense stress related to the tasks of daily living and realize that we are alone with our problems. To avoid the "revolving door syndrome," we must receive adequate support to stay involved with community life and sufficient encouragement to grow towards greater autonomy. The assistance and concern of the community at large is crucial to our success.

Tragically, we continue to be effectively zoned out of many communities by their ignorance and fear. Current state zoning

laws must be amended to allow the establishment of housing alternatives for us in our communities. Incentives must be developed to encourage private sector funding to this end. Residential facilities such as group homes, halfway houses, boarding homes, and nursing homes must be better maintained and managed if they are to contribute to our stabilization and recovery.

Residential alternatives to hospitalization are critical to our being able to successfully reintegrate into our communities. Due to problems with stigma and zoning, these housing options are extremely under-represented and many individuals who could be receiving help are instead inappropriately confined to hospitals because there exists an inadequate number of residential alternatives. Existing resources must be reallocated from institutions to community-based facilities, and these programs should be expanded and reliably funded.

We must establish crisis houses in the community, utilizing consumers as staff, if we are to provide effective treatment services and to limit expensive, often unnecessary, inpatient stays in hospitals. We need a system of 24-hour crisis intervention with the capacity for home visits. Often long-term hospitalization can be averted by a caring person who has shared similar experiences and feelings spending some time with a distressed individual. I would argue for hospital alternatives that are patient-conceived and patient-controlled.

We need a continuum of residential treatment intensities offering a wide range of subsidized housing for clients. Local governments could ensure adequate housing through subsidized rental units, converting abandoned housing, or sponsoring group living arrangements. There is a new program in Denver called the "Companion Program" which is training a group of people who have had mental illnesses to assume the role of live-in companion and peer to another person with a mental illness. In exchange for giving assistance to the roommate with activities of daily living, the companion will receive free rent in an HUD-approved apartment, vocational assessment and planning, and training opportunities. The roommate, in turn, will receive help from a peer in living independently, an opportunity for HUD Section 8 housing, training in various skill areas, and companionship. This reflects a move towards promoting permanent, normalized residential living by honoring the clients' housing preferences. This is a major step, for there is no question that minimizing relocations by the client will increase his overall stability.

It is a sad truth that disincentives currently exist to the provision of the most appropriate care for the mentally ill. Not only must we eradicate these disincentives, we must work diligently to establish incentives to provide the best possible treatment. Two major obstacles to this are that public dollars do not usually follow the client form one treatment agency to another and that the catchment area system which still exists in many states does not always work to the client's benefit. In addition, there are many persons with mental illness incarcerated in our jails who are receiving no outreach from the mental health system. The bottom line is that in many cases the location of one's place of residence overshadows receipt of the most appropriate services.

Insurance or other reimbursement now drives the mental health system, another obstacle to quality care for the mentally ill. Our insurance coverage (or lack of it) determines where treatment is received, the nature of the treatment plan, the type of treatment, and its duration. Because of the frequently lifelong and pre-existing nature of mental illness, consumers of mental health services are often denied insurance coverage, forcing us into the public sector and thus removing any degree of choice in our own care.

The practices of third-party payors have resulted in lower benefit levels for outpatient than inpatient treatment, no reimbursement for most non-hospital services, disrupted continuity of care, and inadequate outpatient care which often leads to the patient's being hospitalized inappropriately simply because inpatient care will be reimbursed. This makes no sense fiscally, because in most cases the patient can be treated in the community more effectively and less expensively.

In addition, disability entitlement programs have built-in disincentives which keep many individuals with a mental illness from becoming independent, working productively, and successfully reintegrating into their communities and society. If we work continuously for a certain period of time and earn enough money, we know we will be denied our disability checks. This is a complicated area for the mentally ill, many of whom do not have enough self-confidence to risk losing their guaranteed monthly disability income by attempting employment.

Although we know we can reapply for benefits, we also are aware of the difficulty of this task in terms of bureaucratic paperwork and the fact that we may still be turned down. We need legislatively-mandated social services and income maintenance to be available to every client when needed and we need to establish incentives for returning to employment when ready, and there must be a vehicle for easy transition back and forth between the two. This is a crucial issue, for vocational achievement would go far in combating our characteristically poor self-image and devalued sense of self.

One answer to these problems is for all parties to join together, working cooperatively in coalitions. Historically, there has been conflict between the goals, objectives, and motives of various participants, e.g., the territorial and profit motives of the professional, the helping and support motives of the family, and the empowerment and autonomy motives of the patient or client. Even between provider groups, because public and private sectors are in competition for the same dollars they seldom work together. There has been mutual distrust and even paranoia, and consequently differing points of view on critical issues have not been immediately resolved, resulting in frustration with the system.

We have seen competition for resources and money; for power, recognition and influence; and over philosophies regarding what is best for the client and what the desired outcome should be. Groups have feared co-optation, the taking over of one group by another. Identities are threatened, with possible role diffusion, and compromise may be seen as defeat.

Effective coalitions work because they are based on a partnership model which is non-hierarchical. Everyone is seen as an ally making a valuable contribution and all parties are

equal partners. There is shared work, shared information, shared input on issues, shared decision-making (ideally via consensus), and shared responsibility. There are substantial benefits to a mental health coalition. There is a validation of all viewpoints, improved communication, and improved trust, leading to a reduction of conflict. A broader perspective is fostered. New opportunities for leadership are created. There is a sense of empowerment, both a subjective feeling and the objective ability to effect change.

A coalition serves to broaden and strengthen the power base, and results come easier with a large united front. As an example, in Colorado 60 agencies have formed a coalition to gain legislative support for implementing new services for the chronic mentally ill; to date the legislature has appropriated over $5 million in increased funding as a result of the coalition's efforts. Working together can thus result in the accomplishment of an identified goal, in this case the most appropriate and most effective treatment for the patient, our first priority.

Services should always strive to empower the consumer by ensuring that we retain as much control as possible over our own lives. We should be allowed to set our own goals and to work towards them in our own way, resulting in a success experience. And as we proceed in treatment we clients must hold the service system accountable for its performance; we must vocally express our expectation that these supportive and therapeutic systems will perform their duties to us assertively and on an ongoing basis.

Impact of the Consumer Movement

In spite of what many might see as a slow beginning, our consumer movement is making a difference. We are becoming empowered and are rapidly learning to work with others on changes to which we are committed, and we are making our influence felt. Organizing into powerful bodies of clients and networking with other patients and clients has enabled us to strategize collectively, lobby effectively, and establish credibility. With the knowledge that we are not alone, we are working together in groups for common goals. In addition, because mental health clients possess a strong identification with our peers, we are able to provide mutual assistance in overcoming a common handicap. We provide emotional support to each other, leading to an enhanced sense of personal identity and an assumption of individual responsibility.

Primary consumers now recognize the legitimacy of our own needs and have become active in defining what we want to see in terms of mental health treatment services, and we are participating more often in their delivery. We are discovering that there is strength in numbers and we are beginning to use this ascendancy to exert pressure. We must risk coalition-building, working together with other interested groups on issues on which we can agree, despite possible co-optation. We should not be threatened unduly by this possibility, for even in the face of opposition we can and must remain strong in our convictions.

Indeed, in this and other areas, no longer do we feel powerless. We mental health consumers are beginning to exercise our self-determination and to ensure that our voices are heard as the legitimate voices they are. All of us must fight diligently and persistently to empower ourselves and to reach our goals. We must build on our knowledge that we are not alone, for there is strength and hope in numbers. Consumers must continue to network and to work together for articulation and realization of our dreams. We must publicize our activities and accomplishments in the media, fostering a more positive image. We must be assertive and constantly advocate for ourselves. If necessary, clients of the mental health system must take our battle to the courts. We will need to strategize collectively by organizing into a broad coalition that can lobby from our perspective and for our goals.

I realize that as we struggle to achieve our goals others already in power will feel threatened. This may be inevitable; it may even be healthy. Probably it is a good sign when this occurs, for it means we are making progress; we are being heard and taken seriously. At any rate, although we mental health clients may initially be seen as troublemakers and upstarts -- even radicals -- I feel confident that as time goes on those involved in the present system of care will realize the positive impact we can have and they will be able to relinquish their own stereotypes of us. As they see a new trend emerging, mental health providers will hopefully be able to overcome their own insecurities enough to work with us on behalf of more effective treatment for the mentally ill.

To this end, mental health consumers are taking action now. We are educating ourselves on how to best access the system. We are procuring and studying important documents, checking for interagency consistency and holding these bodies accountable. Others are discovering quickly that primary consumers are exceedingly capable of identifying and documenting problems with the system, publicizing these issues, and making recommendations. We are also keeping abreast of bills and laws that affect us, proposing legislation, and supporting or opposing bills collectively by writing letters or testifying.

Primary consumers are participating on a multitude of boards and committees, forcing others to realize that ours is a unique and necessary perspective now missing. Unfortunately, there is at the same time a tendency to acquiesce to our demands for representation and participation by limiting us to advisory boards as opposed to policymaking bodies. This is a trend with which mental health clients cannot afford to be content. In addition, we are also becoming active in consumer-owned and -operated activities such as peer support groups and drop-in centers. As an extension of this, I see the day when consumers who so desire will be case management personnel, hospital staff, and outreach workers. By working together for these changes, those of us labeled and treated as "mental patients" are overcoming our negative self-images and regaining control over our lives. Such are the fruits of empowerment.

Today's consumer movement is both founded on and dependent upon this empowerment. Through empowerment mental health clients will have control over our own lives and therefore become actively involved in our own treatment. We will have a choice, a crucial component of one's investment in any process. Consumers will be seen as the valuable resources we are -- and utilized. professionals will work with us as equals, as partners in the recovery process, and there will be shared responsibility for decision-making. We will see less

emphasis on the medical model of prescribed treatment and more of the humanistic model of negotiated treatment plans to help the consumer meet his or her basic needs. We will be seen as people, not diagnoses.

Mental health clients will be assisted by professionals, if we wish, not directed by them, yet we will be viewed as the authorities on our illnesses. We will be treated with dignity and respect, as we should be. Personal growth will primarily be promoted through our interactions with our peers. Consumers will once again learn to trust in ourselves. The shame and humiliation we have experienced will vanish and we will have renewed power, confidence, and hope. Clients will no longer be seen as inferiors and subordinates, but instead recognized as the experts we are in this field. Our differences and individual needs will be recognized and respected. The development of effective coping mechanisms and our own self-determination will ensure emancipation from an often paternalistic system of mental health care.

Changing Times

Without question there has already been a change in the mental health system, in large part due to an ever-growing consumer movement. When I first entered it in 1966, patients had few rights and even less of a voice. For example, I was not informed of the decision to give me insulin coma and E.C.T. treatments. A nurse walked into my room one morning with a huge needle and in response to my worried query stated that everything would be okay and that this was "doctor's orders." Furthermore, I was never told my diagnosis and in no way included in any decisions around treatment, much less the dramatic consequences they would have in my life.

In a later hospitalization I became acutely aware of the arbitrary cruelty of the system when I was on a daily basis thrown into seclusion and restrained for the convenience of staff and as punishment. When I attempted to discuss this, I was accused of trying to resist staff and question their authority. I was then forbidden to cross a red line painted on the floor, much less leave the unit. Not surprisingly, I did not improve, as such power struggles and automatic limit-setting are rarely therapeutic. Instead, predictably, the more I was ostracized and punished, the angrier I became and the more I rebelled.

Slowly, however, my desperation turned to resignation and hopelessness. To make matters worse, even my psychiatrist would not speak to me. Although he dutifully came to see me about twice a week (to receive his insurance payments), he completely stopped talking to me after the first couple of sessions. Not only was this "silent treatment" not helpful, it contributed substantially to my feelings of despair. As usual, recovery was never even mentioned as a possibility. The only consistent messages I received from staff and doctor were that I was hopelessly inferior, incapable of functioning successfully, could not be independent, and that I would never get well.

In contrast to this situation, treatment I later received started me on a path towards recovery. Not surprisingly, this occurred at a halfway house located in the community. It was here that I began to put my fragmented and ineffective life back together, a task facilitated by the positive attitude of the staff. Here professionals made it clear from the beginning that they were there to guide or assist me, rather than direct me. Finally, I had some control. I have since discovered that my vulnerability to stress, anxiety, and accompanying symptoms decreases the more I am in control of my life, which is one reason I will never again allow myself to be dependent on a mental health system.

Although this residential program was structured and supervised, I did not feel imprisoned and at the mercy of an arbitrary staff. I sensed immediately that the treatment team genuinely cared about me, and therefore I did not feel an ongoing need to test limits. Unlike the hospital staff, the residential team did not assume authoritarian and confrontational postures that inevitably result in power struggles. Staff perceived the residents first and foremost as human beings, and we were accepted and treated with dignity and respect.

Staff believed in me, a new experience. Interactions were non-threatening; we always knew staff was on our side and available to us for assistance in overcoming the problems in our lives. To help with this, treatment focused on our healthy and adaptive aspects. There was strong staff orientation towards success and an expectation from the beginning that all residents would leave and become independent through the continuing process of building on our individual strengths.

My input into treatment was encouraged and even demanded. During my painful inpatient experience progress had been measured with concepts like "consent" and "cooperate" and "comply" instead of "choose." In striking contrast, the residential treatment team considered me a partner capable of taking an active role in my recovery process rather than a less knowledgeable inferior, which increased my self-esteem and promoted my personal growth. Staff at this facility believed in my potential, and I began to develop confidence in myself. A real sense of ownership in the program and in my improvement was fostered, and gradually I became aware that I was my greatest asset.

As a result of my developing self-confidence and realistic trust in others, I was able to grow. The prejudice I had encountered from previous psychiatric professionals was supplanted by an emerging understanding of me as a person, and pity became respect. The flexibility of the program to meet my individual needs, recognizing my interests and capabilities, enabled me to move forward, with the knowledge that a predictable, consistent, and caring support system was available for me should I need it.

I was fortunate to have been in a program which treated me with dignity and respect, and with much encouragement and support for my efforts to achieve independence and mental health. Until this time I had expected someone else to "fix me." It took many years before I finally realized, after many clinical disappointments, that this task fell to me alone and that no one else could really make me better. This was one of the major discoveries of my life. I approached this endeavor very seriously, conscientiously working to get my life back together. Then, for the first time, I felt ready to take responsibility for myself, including management of my illness, and it was at this point that my recovery really began.

This sense of self-responsibility is the essence of empowerment, the force behind the consumer movement. Unfortunately, it is not something often engendered by the present mental health system. Therefore, we mental patients must

reject the negative images of ourselves that we have learned to internalize and the view of ourselves as impotent, our situation helpless. We must change the image of who we are and what we can accomplish, first for ourselves and then for the public. By organizing with other mental health clients, we are doing this and making changes in our own lives and the care we receive.

Slowly resources are, in some places, being reallocated to community-based facilities. Education is assisting with our acceptance in these communities. Ultimately, the client's right to privacy, confidentiality, and independence must be acknowledged. Because of the consumer movement, we will eventually be accepted and reintegrated into our communities, where we will learn skills, work productively and contribute to society, the society that has traditionally abandoned us.

Conclusion

In conclusion, the role of the consumer movement in mental health is to implement change, changes long needed for our recovery. Ours is a movement similar to the civil rights movement; in many ways we are fighting for the same goals. The time is right, and people are beginning to realize it. What professionals don't seem to recognize is that the changes for which we are fighting are inevitable and that they can either join us in our struggles now or be our defeated adversaries later.

We must continue to fight diligently against ignorance and the prejudice and discrimination resulting from widespread stigma. We will no longer be exploited. Our consumer self-help and advocacy movement will ensure that we are no longer powerless and that our basic needs are adequately met. In the future there will be better training for medical staff, police, and judges. Human service workers, including psychiatrists, will be required to have compassion and respect for people with mental illness, resulting in a mutually trusting relationship and an acknowledgement of the expertise we both bring to this association. Consumers will be included in mental health planning groups and government bodies, where our viewpoints will be seen as legitimate and respected. We have or can acquire the knowledge necessary to develop community programs and we will be involved in policy development and service delivery.

Mental health consumers will eventually succeed in our endeavors for many reasons. We are dedicated, committed because we care about others who are and will be receiving mental health services. There is power in numbers, and we are not afraid to be visible and to be counted. Although we are struggling for scarce resources with individuals termed "the worried well," we will lobby more effectively because they prefer to remain anonymous, while we no longer fear being visible in our communities. Because many of us with long-term illnesses are not afraid of exposure and of speaking up, we will get results.

Consumers of mental health services will, I hope, successfully enlist the support of power brokers and opinion makers in our cause. To further our goals, many of us will someday assume new roles in the mental health system. In addition, alternative services will be increasingly offered by and to clients, and we will receive grants to implement these visions. The patient is most familiar with his disorder and treatment needs and has a valid, even expert, point of view. We realize now that we should be partners in the design and implementation of our own therapies; this involvement will demonstrate that mental health clients are not treatment-resistant but instead only system-resistant.

Today the mental health consumer movement serves as a conscience for the present system of care, and we intend to keep it honest. It also enables us to find ways to use our psychiatric experiences (positive and negative) constructively to improve the system of mental health care, a welcome opportunity for many. We are learning to exercise self-responsibility and self-determination. Mental patients are uniting and speaking with a unified voice, empowering ourselves to become more self-sufficient and independent. We are working both within and outside of the traditional system to meet both our needs and those of our peers.

We did not choose to be ill, but we can choose to deal with it and learn to live with it. No longer do mental health clients feel powerless: forced into treatment, coerced into power struggles, and administered therapy that others have determined to be in our best interest. We are changing the image of who we are and who we can become. We are learning to rely on ourselves and to take an active role in our recovery. We are becoming empowered. The mental health system will not change until it absolutely has to, and, thanks to the consumer movement, that time has finally come.

Excerpts of Reviews & Comments

The following are excerpts of reviews, comments and recommendations made by the 1988 Switzer Scholars. These are presented to further stimulate thinking, discussion and action as they relate to the content of "The Role of the Consumer Movement and Persons with Mental Illness" by Esso Leete.

Esso Leete has presented the consumers' desires for just the array of programs that many of us in the mental health and rehabilitation service systems have been pleading for over many years. So much has conspired to prevent any but localized demonstrations - just enough of them to show that such combinations, such as coalitions, with participation by the consumers and their families, can work. Only lately are these being recognized as rehabilitation approaches, thereby shifting their focuses from medical contrivances to something broader. Rehabilitation means incorporating collaboration between disciplines and among resources, the sharing of guiding responsibility (power, if you will), and the shifting of this power for leadership of the process to the correct member of the team at each appropriate stage in rehabilitation. The client (patient, consumer) must always be a member of the rehabilitation team.

Perhaps, just perhaps, the mental health consumer movement in coalition with others can effect the changes we all want for an effective and dignified service system. I certainly hope so. I wish I felt the assurance that Leete expresses so ably. At the very least the pressure of the consumer movement might make the actors in the health and social service systems who control the service elements sit up and take notice: that inpatient hospital care should give way to outpatient and community services as the central locus of funding and clinical services; that financial support and opportunity for transition to work are not incompatible for a rehabilitee; that serving the mentally ill is not a bottomless budget pit - psychiatrically ill people can get better or stabilize to become productive participants in society; that the stigmas attached to mental illness are unwarranted; etc., etc. And, if the consumer movement can help in changing the attitudes of the professionals who now run the mental health and rehabilitation systems it will have made giant strides toward the goals outlined by Leete.

-Bertram J. Black

Esso Leete's paper provides powerful and convincing evidence that the field of mental health simply must begin using the experience of consumers of service as the primary knowledge base for redesigning current services and planning new ones. Three aspects of the current mental health scene, for example, show just how critical, and how absent, real consumer participation and control is: 1. In reviewing the mental health literature which forms the basis of our training of new professionals and of upgrading the knowledge of current practitioners, there is almost no work written directly by consumers, or work focused on the experience of mental illness, and its meaning to the individual. 2. In the day-to-day functioning of virtually all mental health systems, whether at the state or local agency level, there is almost no consumer control over the planning, staffing, funding and evaluation of services - in fact there is precious little meaningful participation or involvement in these basic functions of a system, in spite of the growing rhetoric about its importance. 3. In spite of the fact that some research and evaluation studies now include measures of "consumer satisfaction," such studies almost never ask consumers, *before* the service is offered, what kinds of services they would be most satisfied having.

In speaking with ex-patients and family members, one finds that Esso Leete's story has many common elements with that of other consumers. Many young people experience a "first break" during the late adolescent years, and are propelled into a long history of hospitalizations, with multiple diagnoses and medications, with the only consistency provided being a poor prognosis, and a disbelief that they could ever return to a "normal life." When individuals do recover and become outspoken advocates, they are often accused of being "atypical," "much higher functioning," and so forth. It appears to be very difficult for society, and the mental health system, to confront the disparity between how people look in terms of functioning in current mental health programs, and what their potential may be, given the kinds of supports Esso Leete describes. She describes well the characterization of patients and consumers as "too sick . . . incompetent . . . and disorganized . . . to speak on their own behalf."

The hope in Esso Leete's paper lies in the helpfulness of the self-help movement as she experiences it, and in the power represented in consumers becoming organized nationally. When one reads her description of **the level of basic rights** that consumers are still struggling for, it becomes clear that change is not only a matter of persuasion and education, but of power and politics. Esso Leete writes movingly about stigma, not in the abstract, but in terms of its day-to-day devastating impact on consumers, on such basic needs as decent housing, jobs, and the opportunity to participate in neighborhoods and communities.

If the concept of a community support system was the radical alternative to traditional services in the 1970s, the next revolution we are experiencing in the 1980s and the 1990s is the impact of consumers and their families speaking for themselves. Esso Leete makes a strong and convincing argument for the critical value of consumer-run services. Clearly, consumer-controlled service alternatives are a critical building block of the community support system of the future. But Esso Leete also describes the need for effective services in general: for services that help with jobs, medical care and crisis intervention, and she argues strongly for the need for case management. Housing, of course, is a key need, and Leete argues for a

variety of options for people which respect their preferences and which are "patient conceived and patient controlled." And she points out the unfortunate reality that the place of one's residence typically limits the services one receives, since people are by no means assured of services regardless of their living situation. They should have that assurance.

Throughout, Leete emphasizes the critical ingredients of client choice and consumer driven services. In fact, broadly promoting consumer-run services may be the first step in an evolution of our thinking about services that will ultimately subject all services and supports to the test of whether they are of a high quality regardless of who is providing them. And a central measure of high quality is the extent to which their conception and operation is subject to the control of the consumers of services themselves.

It should also be emphasized that ultimately, relationships with others who have no obvious difference or disability, are the hallmark of real community integration. Stigma may best be overcome when people with and without a label of mental illness are living and working side-by-side. This has certainly been the case with physical disability and developmental disability movements. But as this paper describes poignantly, such integration starts with power, with having a meaningful voice, and having real choices about how and with whom one will spend time. And this voice begins with promoting the dissemination of consumers' own stories and using them as the basis to improve what all of us do.

-Paul J. Carling

This paper has far reaching implications that would broaden the power base of the mentally ill; establish a unified front which could demand and obtain legislative policies and laws. The consumer movement is empowerment for the mentally ill and their families to bring about change in the pattern of care and mental health services; making them more responsive to the client and accountable for the quality of their services. Consumers must continue to increase their visibility, unifying themselves, gain representation on mental health boards and committees, assemble political support, address and eventually eliminate the stigma. The author advocates that self-help groups are alternatives to traditional therapy, yet a continuum of comprehensive services requires cooperation and coordination between agencies and the consumers. The concept of a mental health coalition is long overdue. There was emphasis placed on effective legislation government housing, zoning, social services and entitlement programs as well as treatment in the most restrictive environment for the mentally ill population.

This paper outlined major issues of clients/consumers and provided detailed approaches to address if not eliminate them through advocacy. Esso Leete reported innovative alternatives for housing, insurance coverage, and dissemination. This reviewer agrees with the author that individual programs for the delivery of mental health services are prerequisite to ensure the achievement of the highest degree of independence. Self-help groups could act as an added entity to the community treatment team, this would embrace the author's concept of a coalition. The treatment team would comprise of specially trained case managers, psychiatrists, social service workers and rehabilitation specialists who have the highest regard for their clients. However, if the team is expanded to include the client, potential and active providers, then, indeed, individual programs would be developed, implemented and experience a greater chance of being successful. There is an ongoing need to document the effectiveness of a coalition in terms of cost effectiveness and clinical usefulness.

-Jacquelyn Dickerson

Esso Leete accurately describes a mental health consumer movement that has been years in developing into the fairly sophisticated phenomenon that it is today. The implication is clear: This is an exciting and crucial time for self-help and funding and other resources should be made available by local, state and federal government and foundations to encourage the development of consumer-run programs such as advocacy programs, drop-in centers, support and social groups, crisis and respite care programs, housing and hotlines. This may appear threatening to professionals but we have seen that care and support from those who have experienced the illness themselves is effective: self-help works and is cost-effective as well! Consumers acting as advocates are also necessary and valuable to any mental health system. People who are using or have used the hospitals, clinics, housing programs, and CRPs need to be monitoring these services. Also, consumers should be hired to work in these programs and be paid a respectable wage, in addition to managing their own programs. Self-help programs are an important link in the continuum of services in the community.

The accomplishments and the impact of the National Mental Health Consumers' Association (NMHCA) recently needs to be recognized when discussing the consumer movement. It is the first truly broad-based representative voice of consumers, advocating for consumers at the national level. In its short life it has taken action in Congress to help develop and monitor the new Protection and Advocacy legislation and it has filed amicus curiae briefs in the U.S. Supreme Court on rights cases. The NMHCA seeks to destroy stigma by presenting positive images to the media of people recovering from mental illness. It negotiates around the country with NIMH consumer needs, including helping consumers apply for demonstration grants. It has helped organize four national consumer conferences and provides leadership training via teleconferences and conferences to consumers. One of the beliefs of the NMHCA is that there should be more consumer representation on mental health decision-making bodies. The Clearinghouse it sponsors offers technical assistance to encourage the

growth of self-help groups around the country.

More consumers need to be made aware of the consumer movement and educated about mental illness and its treatment or non-treatment by the mental health system so that they can be empowered individually to help make system-wide changes.

-Christy Disher

One of the first lessons in any marketing course is the concept that "The Consumer is King". Basically speaking, this concept revolves around the idea that services, products, etc. should be developed according to consumers' desires and needs. As the author of this paper has so vividly pointed out, the makers of policy in the field of mental health have certainly not used this concept as their foundation for creating services for people with mental illness. By ignoring the voices of the people we are trying to help, we have essentially eliminated many opportunities to develop effective programs for helping individuals live with dignity in the community. Indubitably, we are headed in the direction of more consumer involvement in mental health. Programs that do not recognize this fact will soon become obsolete. The author of this paper gives us an insider's view of the deficits in our mental health system along with a description of current and future goals of the consumer movement. The implications are unlimited. I will only mention a few.

All programs and policies must be developed with input by the people that the programs are meant to serve. If we only spent the time that we spend on figuring out how to work with the "resistive patient" on involving these individuals in planning their future, we could eliminate much of what we currently struggle against. Continued funding, recertification, and community support for programs should be contingent on at least an acceptable level of consumer involvement in decisionmaking.

Training for non-mentally ill individuals should stress the importance of consumer involvement in mental health. There should be a special effort to promote the training of individuals who are recovering from mental illness to help others to do the same.

An all out battle on the stigma of mental illness must be waged by all parties involved. The creation of self-help groups enables individuals to eliminate their internal stigmas, while education of the public can help defeat external barriers.

Consumers, advocates, and service providers must align themselves to fight for resources needed to help people with mental illness.

-Ralph Fasano

The single most important message of this paper which is filled with important messages is the author's summarizing and challenging comment that "the changes for which we are fighting are inevitable and that they [professionals] can either join us in our struggles now or be our defeated adversaries later." Two questions emerge from this comment. Do you argue with this conclusion; or , if you agree what is your response? The answer(s) provide a basis for action. The author guides our response by commanding dignity and respect. She leads us to ask ourselves our individual responses to consumer issues. How committed are we to consumer-operated alternatives? Are we willing to ask for more than token funding for such alternatives? Can our coalitions be truly open to consumer representation and will our relationships with them be symmetrical? Can we achieve a personal accountability in a system both publicly funded and guild driven? How many times do we look around the room and say to ourselves, consumers aren't here, but I will make sure they are the next time?

Perhaps, however, as I implied earlier, can we face our own role squarely on and take the discussion of the role of the consumer movement to a new level? The author gives us plenty of opportunities to act out our new-found commitment to consumer involvement. We must choose from the myriad of opportunities and assimilate the challenges into our total view of our world and help others do the same.

-Martha B. Knisley

In recent years the Community Support Program of the National Institute of Mental Health has been particularly vigorous in its Requests for Proposals for consumer-run programs for seriously mentally ill persons. As a grants reviewer for several years, I can attest to the creative and well-presented quality of these proposals, most of which reflected consumer, not professional, conceptualization and design. Esso Leete's beautifully written paper is in this category. As I read it, I wondered about our behavioral criteria for the diagnosis that has been attached to her illness. Where in this tight, well-defined presentation are the loose associations and disorganized thinking of the schizophrenic syndrom? This paper certainly does not reflect thought disorder. It is a logically developed and moving statement of the pain, stigmatization, anger, and growing self-assertiveness of the mental health consumer's experience. Its central organizing principle is the commitment of former patients to be responsible for their own rehabilitation and that of their less functional peers.

Most of the papers in this Switzer Monograph have acknolwedged the range and variability of seriously mentally ill persons. At one end of the curve are severely impaired persons who may be capable of modest improvement but are unlikely to ever function well in mainstream society. At the other end are persons with the potential for leading productive and meaningful lives; some, like Esso Leete, are capable of making highly significant contributions to society. I am not sure about the extent to which professional interventions will facilitate or impede this developmental process. To really be helpful, the professional contribution must be requested, not superimposed; and it must be individually-tailored and sensitively, almost reluctantly, applied. Leet's descriptions of staff providing guidance and assistance, rather than direction, and her comments on the

therapeutic aspects of the patient's feeling in control, are extremely important lessons for professionals to learn.

But this paper asserts that professional ministrations, whether defined as treatment or rehabilitation, are simply not enough. Nor is family support enough. Empathic understanding, role-modeling, and group support from peers seem to offer major therapeutic benefits in the consumer-run alternatives, for both recipients and providers.

This is an important paper, perhaps the most important paper in this series, because it exemplifies the substantive criteria for rehabilitation. We may use a wide range of outcome measures for rehabilitation--role-function, skill acquisition, job placement, and the like--but Leete educates us that no long-range change can occur until clients begin to feel respected and in control of their own lives. Psychotherapy and insight are not necessarily the avenues to this; from Leete's personal report, respect and appropriate expectations from staff were the turning points in her own self-evaluation.

This is in accord with one of the major lessons from transcultural psychiatry (Lefley, 1984). The course and prognosis of major mental illness may be affected by cultural attitudes, which of course influence the self-perception of the person with the illness. The import of Leete's paper is that destigmatization of the mentally ill must begin with the attitudes of the healers, and be nurtured by societal respect and empowerment. Opportunities for organization of former mental patients, consumer-run programs, and job training and placement for mentally ill persons in the human services they know so well, will provide the most direct routes to rehabilitation and reintegration into productive social roles.

Leete has outlined a number of policy changes needed in service delivery and community care. Examples are modifications in Social Security practices which currently penalize continuous employment; greater availability of insurance coverage; disincentives for third-party payment practices which favor inpatient over outpatient treatment; and greater provisions for continuity of care. Service linkages are needed between consumer-run projects and the professionally-run agencies which must continue to deliver essential traditional services to those who need them. An exclusionary policy should be avoided at all costs. It should be possible for service recipients to receive chemotherapy, psychotherapy, crisis intervention, support groups, or social/recreational and educational services in a variety of sites without penalization and without being owned as a "client" by this or that program.

Certainly we need a comprehensive analysis of vocational rehabilitation programs for people with mental illness, many with superior intelligence and advanced skills. Legislation is needed to assure continued funding of consumer-run projects, and evaluation research to determine their long-range outcome. Cost-effectiveness is obviously an important dependent variable, since consumer-run projects may eliminate high professional salaries and administrative costs. Alternatively, we need to learn whether the typically extensive reporting and accountability requirements of most publicly funded service programs will dampen enthusiasm or impose too onerous a burden on administrators new to bureaucratic systems.

In these consumer-run projects we have the possibility of creative research on high-functioning mentally ill persons as mentors and role models for lower-functioning counterparts; on the effects of peer group support on symptom remission and self-esteem; on the working out of control and dependency issues in peer group context; on the roles and effectiveness of former patients as human services providers; and on political action as a therapeutic modality. The applications of rehabilitation principles, when administered by individuals who personally understand their potential to effect change, may also contribute substantively to rehabilitation technology.

In developing and planning services for mentally ill persons, consumer input must be more than an advisory role in program design. Professionals need to learn about the experiences and developmental insights that Esso Leete has so eloquently described in this paper. They must know something of the phenomenology of mental illness, the consumers' experiences in surviving and overcoming, and their evaluation of what helps and what doesn't. We must give vigorous encouragement to a role for primary consumers in the education of clinicians, rehabilitation specialists, and other mental health professionals at all levels of training--preservice, inservice, and continuing education.

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-Harriet P. Lefley

Leete has written of the role of the consumer movement within the mental health system; I am left wondering what the force of the consumer movement would be if persons with psychiatric disabilities and persons with physical disabilities would join together in one disability rights movement. Advocates of disability rights do not deny that their movement does not include a primary concern for persons with psychiatric disabilities. Why must the battle for civil rights be fought over and over again? Why do advocates of independent living reserve "accessible" for architectural barriers?

The state/federal rehabilitation system must actively encourage consumer input as regards rehabilitation service delivery. State rehabilitation agency personnel must be educated to understand the long-term support needs of persons with severe psychiatric disabilities, and must become optimistic regarding the outcome of service delivery with this population. It would be nice, for once, to hear a rehabilitation counselor, or rehabilitation supervisor, or rehabilitation educator say, "Supported employment will work."

As Leete noted, we must do more to serve persons with dual diagnoses; in addition to those mentioned, we must be concerned with providing for the mental health needs of persons with

head injuries. "Peer-providers" as a viable service needs to be expanded within the mental health system, and needs to be introduced within the state rehabilitation system. Closer cooperation between these two systems has been mandated; understanding must also occur. Rehabilitation has a long history of suspicion when it comes to both the mental health service system and to working with persons who have chronic mental illness. It is time for rehabilitation professionals to become more honest with how we indeed view the consumer who has a psychiatric disability.

We advocate "hire the handicapped," but do we not really mean "hire the person with a physical disability?" Are we ready to educate and train persons with long-term mental illness to be rehabilitation counselors? Are we ready to hire persons with long-term mental illness to work in state rehabilitation agencies? Are we ready to truly accept persons with long-term mental illness?

-Catherine A. Marshall

The consumer movement has indeed had a very positive effect on rehabilitation legislation. Evidence of this is seen by the development of the Individualized Written Rehabilitation Program (IWRP) and the development of consumer advisory committees for state vocational rehabilitation agencies. In addition, the Client Assistance Program (CAP) was established to assist consumers who were experiencing problems with vocational rehabilitation or had questions about the state agency.

These changes have come about gradually and most people are accepting of the changes. However, there continues to be resistance to accepting persons with psychiatric disabilities. Some of this is due to ignorance on the part of the community. Sensationalism also plays a large part in shaping the images people have of persons with psychiatric disabilities.

If philosophies of treatment are to continue to improve, efforts must be made to enhance the image of the psychiatrically disabled. This will necessitate a joint effort by consumers, mental health professionals and rehabilitation professionals.

If people with psychiatric disabilities are indeed to be given the opportunity to demonstrate their potential productivity, a unified effort will be needed.

-Robert J. Neuman

I found Esso Leete's paper among the best I have ever read in presenting the consumer viewpoint on all aspects of mental disorder from the need for integrated services to the importance of client empowerment. She reiterates the themes found in the papers prepared by Drs. William A. Anthony and Agnes B. Hatfield regarding the importance of personhood, the disabling results of clienthood, the need to help people manage their symptoms and other disabiling consequnces of serious mental illness, the ability of people to make choices, and the detrimental consequences of negative staff attitudes on client growth and success.

I thought the most important lines in this paper were the first two--"I am a person, an individual, a human being. I happen to have schizophrenia." I believe these sentences embody the attitude change and new awareness that we in the mental health and rehabilitation field must strive for during the next decade, if we are to advance the goal of improving the quality of lives of people with mental disorders. If we continue to adhere to traditional, time-worn attitudes of clienthood and people as diseases with permanent deficits amenable only to long-term, professional interventions, and if we continue to discount the consumer viewpoint, we will never move beyond maintaining people, and we will do a great disservice to the two million individuals with serious mental disorders in the nation, as well as to the nation in its loss of the potential contributions of valued citizens.

I cannot add anything to this comprehensive, articulate, germane paper other than a remark from the perspective of the NIMH Community Support Program (CSP) and some recommnded actions to operationalize the ideas and concepts offered by Esso Leete. As part of CSP, I was very gratified to read of the initiatives that Leete pointed out as being helpful and important in promoting consumer involvement such as the teleconference project, National Mental Health Consumer's Association Clearinghouse, technical assistance to self-help groups, and national consumer conferences. During the past five years, CSP has been involved in supporting these efforts, as well as others to facilitate consumer participation in program planning and policy development and to increase the number of consumer-operated alternative programs. The most recent 1988 CSP initiative involves supporting approximately nine three-year projects to demonstrate and evaluate consumer-run alternative programs and disseminate the results to encourage replication of similar initiatives.

Promoting consumer involvement and consumer-run alternatives will continue to be important CSP goals. However, I believe we must also do the following to address the problems and move in the directions set forth in Esso Leete's paper:

- Increase consumer representation on all advisory councils, planning boards, workgroups and task forces that provide serious input into mental health services planning and provision, such as the councils currently being formed to develop comprehensive mental health plans in accordance with the mandate in P.L. 99-660. Ideally, the composition should be one third primary consumers (those directly receiving mental health services), one third family members, and one third professionals/providers.
- Every state should develop and implement accountability mechanisms with the ultimate accountability being to the users, the primary consumers and family members. They should be involved in designing program assessments, determining acceptable outcomes, and gathering the information. This will help to assure that good programs (good in the eyes of the

users) will thrive while other less effective approaches are either modified or phased out.

- Every locality should have at least one client-run alternative program supported with state and/or local mental health funds.
- No service or support for living, learning, working, and socializing should be provided in a formal setting that could be provided in a natural setting.
- Every individual in a pre-service and in-service training program should be exposed to the concepts and ideas in Esso Leete's paper. Clients should be used in the class room. Internships and other on-site experience should be provided only in rehabilitation programs based on positive attitudes and in self-help programs, to the extent possible.
- Formal mental health programs should start hiring clients to provide them with employment, serve as role models to other clients, and set a positive example for community employers.

As Leete asserts, we must implement "consumer-driven" services. The ideal system included in the NIMH document, "Toward a Model Plan for a Comprehensive, Community-Based Mental Health System," is a client-centered system. A number of states such as Vermont, Ohio, Connecticut, Tennessee, and Rhode Island are beginning to develop plans based on the mission, values, and principles in the model plan document. Other states should be encouraged to do the same.

While I discussed attitude changes in my reactions to Dr. William A. Anthony's paper, I think it also related to the points in Esso Leete's paper. Basically I believe we need to replace reactive generalizations about the need to address stigma with a proactive stance promoting a new vision of positive attitudes and beliefs (so well-described in Leete's paper that we insist the general public, as well as the mental health field embrace. Although there are many more, I would like to direct attention to the following four: 1. Clients can recover--The evidence for this statement and the profound implications are described in my reactions to Dr. Anthony's paper. I would like to see the field launch a powerful national campaign to counter the injurious and unsubstantiated assumptions about the potentials of people with serious mental disorders to recover and to live, learn, and work in the normal community.

I propose the use of the simple slogan, "Right to Recovery," as the theme for the campaign. "Recovery" embodies the positive, hopeful message that we need to convey, and "rights," characterize a proactive stance. People with mental disorders have the right to the services and supports they need to recover, to live, learn, and work in the normal community setting of their choice. We place so many obstacles in the way of people with mental disorders that we truly deny their rights. We deny them basic civil rights (forced treatment), decent income (poverty level disability payments), and opportunities to live (restrictive zoning), learn (college readmissions denied after an episode of mental illness), and work (employer discrimination). The concept of rights in our democratic, humane society conveys a powerful image with a deep emotional appeal.

-Jacqueline Parrish

Esso Leete, after explaining the role of self-help and consumer advocacy movements and the effects of stigmatization in this country, describes patient-controlled options within mental health treatment and rehabilitation distinguished by the absence of mental health professionals. She clearly delineates the benefits of such approaches including peer support and modeling, opportunities for non-threatening reality testing, social acceptance, and most importantly, empowerment and ownership--controlling one's own life. Leete then, comprehensively and with depth, presents current problems in mental health system delivery--the lack of a broad and a coordinated system of a continuum of services, the absence of client determination in choosing a program, the lack of accountability by service providers, and the absence of funding resources following the patient in the service system.

Probably most importantly in reviewing the impact of the consumer movement, Leete tackles the issue of the resistance of mental health professionals to this burgeoning group. For consumers to make decisions about their own treatment and to participate in its delivery is indeed threatening to mental health professionals. Regrettably, even within the hierarchy of the mental health profession, certain members are still battling for full acceptance as members of the treatment team. Consumers demanding this acceptance will be considered as outrageous. In all likelihood the more institutionalized the treatment setting, the more threatened the professional will be. Professionals will need to explore and overcome their biases, to exercise open-mindedness and a leap of faith in working with consumer-run programs. Professionals will also need to be brought out of their hospitals, mental health centers, and community based programs to participate on-site in consumer-run services. If substance abuse counselors can well service substance abusers, and hearing impaired persons can well serve the hearing impaired, who says recovering mental health consumers cannot well serve mental health consumers?

If one draws a parallel to the family movement within mental retardation and developmental disabilities, then the results of empowerment of mental health consumers and their families has the potential of broadening and expanding community based program services, overcoming community opposition and stigmatization, and setting legislative and administrative policies which are truly in the best interest of the consumers. Most importantly, empowered consumers will view themselves as self-determining, responsible, and worthwhile.

-Carole Schauer

Consumer's Perspective: Summary of Recommendations

The following is a summary of the recommendations for action developed by the 1988 Switzer Scholars as they relate to "The Role of the Consumer Movement and Persons with Mental Illness" by Esso Leete.

I. Recommendations to Enhance Service Delivery:

1. A priority in terms of mental health service dollars should be the development of more consumer-run programs, e.g., drop-in centers, support groups, social groups, consumer businesses, and crisis services.

2. Client-centered case management in a comprehensive community support system must be available for every long-term client.

3. Further development and expansion of the following service programs needs to occur: a) mobile community outreach teams; b) 24-hour crisis intervention system with the capacity for home visits; and c) comprehensive psychosocial rehabilitation programs.

4. Primary consumers should be hired as patient/client representatives to settle grievances which occur in inpatient and outpatient settings.

5. Diversion programs offering alternative living environments must be developed to better serve persons with long-term mental illness confined in jails for misdemeanors.

II. Recommendations to Enhance Policy or Program Development:

1. A system of mental health care where the dollar follows the client should be developed, as well as financial incentives for the provision of services in the least restrictive and most cost-effective setting.

2. Client representation on policy-making mental health/rehabilitation boards and committees, as well as participation in program planning, program monitoring, and program evaluation, should be required.

3. Primary consumer salaries within the mental health/rehabilitation service systems must reflect the level of expertise the consumers bring as program consultants, program directors, peer counselors, case mangers, etc. Consumer positions should be available in a range of opportunities and must reflect the importance of having consumers on the team, e.g., permanent positions with job security versus demonstration projects, full-time employment with complete benefits packages versus part-time employment with no benefits. Within a range of opportunities available, primary consumers can choose to what extent they want to enter the workforce given their disability needs.

4. Standardized procedures must be developed and implemented for referral between private providers and mental health centers in order to develop greater cooperation between the private for-profit and public sector agencies.

III. Recommendations for Training the Public and Staff:

1. Primary consumers should establish education and information programs regarding mental illness for professionals, judges, attorneys, law enforcement officers, family members, and other consumers.

2. Specifically, an effective curriculum for professional schools regarding the treatment of persons with psychiatric disabilities should be developed. The curriculum should include consumer-directed and consumer-evaluated experiential internships, with students having first-hand experiences as the recipients of seclusion, restraints, and psychotropic medications.

3. An ongoing effort is necessary to educate employers about working with persons who have long-term mental illness and about the need to include mental health benefits in their insurance packages for all workers.

4. Mental health program directors should require that professional staff in publicly-funded mental health facilities receive regularly-updated training in working with persons who have psychiatric disabilities.

5. Special training programs must be developed and implemented to train professionals who work with individuals with more than one diagnosis, e.g., consumers with substance abuse problems, mental retardation, or physical disabilities.

6. Special training programs must be developed and implemented to train professionals who work with individuals with psychiatric illnesses who are members of special populations, e.g., consumers who are elderly, members of ethnic minorities, people with hearing impairments, children and youth.

7. Incentives to encourage practitioners to work with persons who have long-term mental illness need to be developed, e.g., training stipends with pay-back requirements being satisfied by service to this population.

IV. Recommendations for Research:

1. The National Institute of Mental Health, the Rehabilitation Services Administration, and the National Institute of Disability and Rehabilitation Research should fund research, including consumer-controlled research, to investigate the consumer role in mental health/rehabilitation service systems, e.g., the impact of consumer involvement on service recipients and on service providers.

V. Recommendations for Federal, State and Local Legislation:

1. Mental health insurance and medical insurance must be accessible, affordable, and comprehensive in coverage for persons with long-term mental illness. If necessary, consumers should work with state insurance commissioners to develop group policies such as are currently available to professional organizations.

2. Social Security laws must continue to change to meet the current needs of persons with long-term mental illness, e.g., changes in Supplemental Security Income made possible with

Section 1619 should be expanded and made a part of Social Security Disability Income.

3. There must be legislation to mandate affirmative action, specifically the hiring of primary consumers in mental health/rehabilitation service systems. The affirmative action requirement should be tied to funding form the National Institute of Mental Health and ensure that consumers are hired at all position levels, e.g., administrative staff, professional human service providers, support services staff, and peer providers.

4. Grant announcements must be made accessible to consumer-run programs.

5. The Protection and Advocacy legislation must be expanded to allow for the investigation of inefficiency and abuse by the Social Security Administration of persons with psychiatric disabilities.

VI. Other Recommendations

1. Primary consumers should work with the American Bar Association and professional mental health/rehabilitation associations to encourage pro bono work with persons who have long-term mental illness.

2. Consumers should consider advocating for continued funding of the National Institute of Mental Health's Community Support Program and for more demonstration projects directly involving primary consumers. Funded projects must include a commitment by the local or state administrators to continue funding projects involving consumers.

3. Consumer groups such as the National Mental Health Consumers' Association and the National Alliance of Mental Patients should network with other consumer groups such as family groups and physical disability groups to advocate for common needs, i.e., increased accessibility to independent living services, and identification of persons with psychiatric disabilities not currently receiving services.

Readers: What do you think about the ideas in this Switzer Monograph?

The National Rehabilitation Association invites controversial and non-controversial comments.

Let us know what you think.

Write:

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The Role of the Family in the Rehabilitation Process

Agnes B. Hatfield

That families might be seen as playing an important role in the rehabilitation process of those persons suffering from long-term mental illnesses may not be readily apparent to those who have not been close to the family movement. However to many in the field, the National Alliance for the Mentally Ill (NAMI) has become one of the most powerful forces for change for care and treatment of the mentally ill to develop in the past decade. Most apparent, of course, has been its increasingly powerful role as lobbyist on all levels of government. Perhaps less well known are the collaborative roles that many families play with providers of rehabilitation and residential services who serve their relatives. Still less frequently acknowledged is the fact that a large percentage of families in this country are still the primary, and often the only, agents of care and rehabilitation for their relatives.

Each of these family roles will be discussed in this paper as it relates to the process of rehabilitation. The family role can be more fully understood, however, if we first review the purposes and ideology of the National Alliance for the Mentally Ill (NAMI) which most members subscribe to and which has had such a growing influence on the way that community services are provided.

Agnes B. Hatfield, Ph.D., the Director of Professional Education with the National Alliance for the Mentally Ill (NAMI) in Arlington, Virginia.

Only in very recent years in the United States have people with mental illnesses and their families had a viable constituency to advocate in their behalf. This came about in 1979, when a number of local self-help groups for families in various parts of the country discovered each other's existence and came together to form the National Alliance for the Mentally Ill (NAMI). In the past nine years, what was once a collection of groups scattered throughout the country, has become a powerful movement able to influence the direction of service giving in a significant way.

In terms of numbers, the development has been impressive: there are now approximately 900 local and state affiliates in all 50 states with an estimated 80,000 individual members. Its rate of growth remains steady with a current growth rate of about 15 percent per year. NAMI supports itself through generous contributions of its members and through foundation grants, and it has been able to establish a well-staffed office in the Washington, D.C., area. The staff leads the advocacy efforts on the national level and serves a consultative role to state and local affiliates.

When NAMI emerged on the mental health scene less than a decade ago, it was generally considered by the professional community serving the long-term mentally ill to be long overdue. It was expected that this new advocacy group would call attention to the gross neglect of patients with serious mental illnesses, and that its members would be vigorous in pressing for appropriations for treatment. In the judgment of many, these expectations are increasingly being met. The amount of media attention to mental illness has risen dramatically and increased pressures on legislatures have brought in new dollars for services. Although the funds are nowhere what they ought to be, the achievements have been good considering the serious fiscal restraints suffered by most social programs in the past eight years.

What was not anticipated by the professional community and society at large was that members of NAMI movement would not only be interested in increased dollars, but that they would also be vigorous participants in the various debates dominating the field of mental illness regarding theories of mental illness, the kinds of research that ought to be done, and the political forces within the various core disciplines that shape the way the mentally ill people and their families are

served. Family members are not neutral in the various controversies that swirl about in these fields; too much is at stake for themselves and their loved ones. The traditional deference to any statement made by someone with a professional degree has largely vanished. Instead, families and patients have come to see themselves as experts in their own right having been educated by the grim realities of mental illness known first hand. This kind of expertise coupled with the technical knowledge provided by the national organization provides a kind of authoritativeness difficult to ignore. Social planners, academic institutions education professionals in mental illness, and service providers must seriously take into consideration the NAMI perspective lest their work become largely irrelevant when implemented in the community. In this paper, we will identify some of the most important and strongly held views of the organization which influence the positions that it takes at this time.

New Definitions of Mental Illness

We recall that participants at the founding meeting of NAMI in 1979 had little difficulty in deciding the focus of their new organization. There was little debate about the target group--it was to be those with "mental illnesses". Families who lived with mentally ill members on a daily basis found the onset of mental illness so dramatic, so awesome in the way that the personality is affected that they felt it could in no way be mistaken for adjustment disorders or "mental health" problems. These families were convinced with a certainty that comes out of a profound experience that this was something different. This was a real illness, a disease.

NAMI members are now aware that they are involved in one of the great controversies in mental health of our time: How can we best conceptualize the severe and long term psychiatric disorders? Should we construe these illnesses as a mental health problem lying on a continuum ranging from the minor stresses of everyday living to the severe disturbances of schizophrenia? Are the differences between lesser adjustment disorders and schizophrenia essentially quantitative in nature with differences being primarily a matter of the severity; or is schizophrenia something quite different and unrelated to adjustment difficulties? It is probably no accident that NAMI had its origins at about the same time that great strides were being made in biomedicine and the study of brain biology. Emphasizing the significance of new research in neuroscience, Judd (1986), now Director of the National Institute of Mental Health, said "it is quite clear that the developments and discoveries from the biological sciences will shape, in very basic and fundamental ways,the practice of psychiatry in the future? (p. 13) As psychiatry is influenced, we predict, so will the other disciplines in mental illness be influenced. "The field (of biological psychiatry) is growing so fast" notes Sabshin (1986), Medical Director of the American Psychiatric Association, "that it becomes gratuitous to point it out" (p. 48)

Many professionals in the field of mental illness were strongly influenced in the past by the psychoanalytic movement that produced great intellectual fervor in this country and strongly influenced theories of mental illness. The influence was such that for many decades inquiry about the brain and its biological processes was neglected and inquiry into psychological explanations of these illnesses predominated. The neglect of brain research was also delayed because there was until recently a lack of sophisticated technology to study brain mechanisms (Judd, 1986; Sabshin, 1986)

It is instructive to contemplate the evolution of new concepts of mental illness when we study similar developments in the field of autism, which occurred just a couple of decades ago. Schopler and Mesibov (1984) provide a brief historical overview: Kanner first identified autism 40 years ago, and since this identification occurred in a period of psychoanalytic dominance, autism was considered an emotional disturbance caused by pathological parents and amenable to treatment by psychotherapy. As a consequence of research and the advocacy activity of the National Society for Autistic Children (NSAC), the definition of autism changed to that of a developmental disability and was no longer considered a "mental health" problem. As a consequence of this changed definition, there developed better community understanding, more effective social policies, changed attitudes toward parents, and appropriate behavioral training for those disabled by autism. Clearly how we define a problem can make a world of difference to those affected by it. NAMI members believe that if "mental illness" separates itself from "mental health", it can have profound consequences in changing funding patterns, developing more positive attitudes toward families, providing for specialty training in mental illness and reducing stigma.

Of central importance to this paper, is what affect does this way of defining mental illness have on the practice and theory of rehabilitation? Some practitioners in the field have expressed concern that if families see mental illness as a physical illness, they will value medications as the only useful treatment and they will fail to see the importance of rehabilitation as a part of the treatment process. We don't think that is happening. While most families do value medication because of some of the dramatic changes that they see in their relatives when they are so treated, these families are fully aware of the residual impairment that often accompanies these serious disorders. With schizophrenia there are usually negative or deficit symptoms such as low motivation, flat affect, and social withdrawal that do not respond to medication (Andreason, 1984). Rehabilitative processes are not the only viable treatment for these symptoms. Families are also aware that severe mental illnesses have devastating consequences for the developmental processes of adolescents and young adults. The cognitive disorganization and inner chaos which these people experience during their crucial years of growth interfere seriously with the social learning that should occur during this span of life and leaves them unprepared for the mature roles of adulthood. Families look to rehabilitation practitioners to help their relatives overcome some of these developmental deficits.

Consumer Empowerment

Until the emergence of the National Alliance for the Mentally Ill (NAMI), there was essentially no input in service planning by consumers. Historically those who used and/or paid for mental health services and who were most personally affected by treatment outcome had little to say about their quality and appropriateness. A benign authoritarianism

prevailed that bred passive and compliant consumers (Dewar, 1978; McKnight, 1977). Hollander (1980) believes that we are in a period of great change in which a larger culture-wide ideology is beginning to assume that consumers are capable of making their own decisions about service needs. Families see themselves as "customers" who as a matter of right and good economics, insist on knowing the nature of the services offered, evidence as to their effectiveness, their inherent risks, and an accurate projection of cost-benefit. They insist that professionals live up to the stated ethical principles of their professional organizations, and they become vigorous in policing their organizations' members.

Families of the mentally ill want the power of informed choice. They want safe, efficacious, cost-effective help for their relatives and for themselves. They want increased control over their own lives. Families want providers who are willing and able to explain their theories and practices, the risks and benefits of their procedures, and a description of alternatives that might be considered. (Hatfield, 1985). Local NAMI affiliates serve as "lay referral networks" (Gottlieb, 1976) in guiding members to services that other members have used with satisfaction.

Rehabilitation services are usually publicly provided, and as such, present special kinds of consumer dilemmas. Publicly supported services usually have a virtual monopoly on a particular service and thereby limit the choices consumers can make. High demand and low supply tend to increase the power of agencies to resist change (Meenaghan and Mascari, 1971). Consumer pressure, then, must come through assessments of their members' satisfaction and active involvement in advisory boards.

The Self-Help Ideology

The National Alliance for the Mentally Ill is a voluntary association with the ideology of a self-help organization. Self-help organizations are unique "power to the people" groups in which people struggle to overcome their sense of helplessness and inferiority in the face of some life challenge (Gartner & Riessman, 1977; Katz & Bender, 1976; Lieberman & Borman 1976; Vattano, 1972) There is general agreement among these writers that people are seeking a new egalitarianism, seeking to become less dependent on professionals, and are according more respect to lay persons in their everyday struggles with particular problems. Bureaucratic definitions of problems are strongly resisted: people want to define their problems in their own way.

The commitment to become truly self-help in nature pervaded the first NAMI convention. Although some participants thought that everyone concerned about mental illness should have an equal voice in the organization, that point of view did not prevail. Participants argued forcefully that other segments of the community--mental health professionals and mental health bureaucracies, in particular--had their own legitimate, but special, interests in mental illness, and that these interests did not entirely coincide with those of the consumers. Further, it was noted, professionals have their own power base in their professional organizations, in which non-professionals are not accorded membership. NAMI was to become the lay equivalent of a professional organization for consumers. Since care-providers have little power in NAMI, the organization can fully represent, to the public and to funding sources, a truly consumer interest. This is thought to result in more effective advocacy.

The Family Role in Rehabilitation

Psychiatric rehabilitation, originally inspired by the enormous developments in physical rehabilitation, Liberman (1986) recently stated, has now acquired its own conceptual base from the "vulnerability-stress-coping-competence" model of mental disorder. Advances in conceptualization of rehabilitation developed by Anthony and Liberman (1986) were simply defined in a recent professional journal as remediating disabilities and compensating for handicaps. The clinical practice of psychiatric rehabilitation, like its counterpart in physical disability, involves two types of interventions: 1. patient skill development and 2. environmental resource development. When rehabilitation is defined in this way, it becomes apparent that families of mentally ill persons play a variety of roles in the rehabilitation process. Sometimes families serve in lieu of professional practitioners and the family itself serves as the agent of rehabilitation. Often the family collaborates with the professional practitioners who carry the primary responsibility for rehabilitation. The families of the NAMI organization are probably best known for their advocacy efforts in securing more community resources for those disabled by mental illnesses.

Families as Agents of Rehabilitation

It is now generally recognized by NAMI members that only a small percent of those with seriously disabling mental illnesses are actually participating in a rehabilitation program. The exact number who are not now receiving services is not known, but Ronald Manderschied in the Biometric and Clinical Applications Branch of the National Institute of Mental Health, estimates that only about 15 percent of those in the community may be participating in an organized program. (personal communication, May 3, 1988). We have no data that indicates what the other 85 percent of patients residing in the community are doing. Since almost all of NAMI families are in contact with their mentally ill relative, NAMI members would be a good source for this information. To date no nationwide survey to elicit such information has been reported. Families could tell us what kinds of services are available in their communities, why their relatives are not taking advantage of existing programs, and they could probably tell us what kinds of programs would be suitable to their relative's needs.

It is safe to say that in the meantime, many families are themselves striving to remedy social deficits and to create an environment conducive to their relative's development. We know little about how families go about the process of providing learning experiences, in the home, or how they use the ongoing activities of an ordinary household in enlarging their relatives' horizons and enhancing their coping skills. It is probable that many families have inadvertently developed ways of doing things that might well be emulated by professional rehabilitation services. It is probably true also that there is a large segment of these family caregivers that are baffled by their relative's behavior and are desperate for help.

We believe that the majority of this group of families would very much prefer that their relative be in a community-based rehabilitation program. They probably feel no alternative to serving in this capacity if no program exists or their relative continuously refuses to take advantage of what is available. Perhaps programs to guide and support these families through this transitional period would be in order.

We have come to the conclusion that there may be significant advantages for some people with mental disorders not to be socialized into the mental health system. Clients are apt to be socialized into certain kinds of compliant behaviors and preoccupation with mental illness and disability that does not serve them well in the wider community. As a mental health client one usually has only other clients as role models; it would be better if they could choose role models from a wider array of people that a larger community could provide. Once one is fully socialized into the client world, it is difficult to become integrated into the larger society. We believe that it is important to learn to identify those that might prefer to avoid being socialized into the client role and look for ways to direct them along a different path.

There seems to be one subset of the mental illness population whose defensive style for handling mental illness is avoidance of all thinking about it. In her analysis of patient adaptive styles, Godschalx (1982) identifies a subgroup that tends to focus away from their mental illnesses, ignores that compartment of themselves, and concentrates on daily activities and relationships. They frequently minimize symptoms, have little or no curiosity about their illness, and think about their situation only enough to take psychotropic medication when necessary to avoid psychotic symptoms. Although some authorities believe that the best adaptation to mental illness is to acknowledge the illness, grieve the losses, and integrate the psychotic experience into life's experiences rather than "sealing it over" (McGlasham, Levy, and Carpenter 1975), we know too little about the consequences of various adaptive styles to recommend a single mode for all patients at this time.

People who can make it satisfactorily without entering the client world are probably higher functioning people whose florid symptoms control relatively easily and whose deficit symptoms are not too severe. They may be extremely resistant to the way most professionals define mental illness and they conceptualize the problem for themselves in a way that they can come to terms with the dilemmas it presents. This subgroup of people must be unusually willing to struggle to master symptoms and identifying behaviors so that they can "pass" as normal. In some cases only their family and the treating physician know that they have mental illness. We don't know how many people fall into this subgroup, how well they and their families manage, and what kinds of help, if any, could make the process easier and enhance the outcome. We believe this is an interesting group to study and that responses to them might take different directions.

It may be that families and providers alike are too prone to think of rehabilitation in terms of clubhouse models, community rehabilitation centers, and therapeutic residential care. However if we use the Anthony and Liberman definitions of rehabilitation cited above, there may be many ways that rehabilitation can be furthered. There are an array of places that individuals can go and learn--museums, adult education classes, recreation centers, churches, theaters, and so forth--which integrates the client into the wider society (Kanter, 1985). We believe that a lot of creative imagination needs to be brought to bear if we are serious about serving the full range of people who could benefit from the attention of skilled helpers.

Families as Collaborators in Rehabilitation

Most professionals now acknowledge the need to relate meaningfully to families of mentally ill persons (Ryglewicz, 1984). There is little agreement, however, as to just what should be the nature of that relationship. Most families seem to want to be involved with their relative's treatment in a meaningful way and often assert their right to do so. They point out that they are the ones most continuously involved in the life of the client over time, that they are the ones who step in when the system fails, and that many families serve as direct caregivers when nothing else is available. In addition, these families point out that they are the ones that often pay the costs and that they are the ones most affected by the outcome.

The word "collaboration" is frequently used by families and providers alike to characterize the kind of relationship that many favor. We assume, however, that the word "collaboration" has taken on many meanings and that an agreed upon definition is called for. We believe that the term "collaboration" should be used to describe a relationship between families and providers which is based on a sense of equality, in which decisions are arrived at jointly, and in which responsibility for the outcome of the decisions is shared. The act of collaboration assumes that each of those involved has an area of expertise to contribute and that decisions made without all affected parties included is inherently unstable. The act of collaboration also assumes that stress and burnout is lessened when burdens and responsibilities are shared. This is just as true of professionals as it is of clients and families. Having said this, however, we believe that a collaborative relationship is not an easy one to develop and that we need to examine and overcome the barriers that exist.

1. Traditional socialization into hierarchical roles that separate professionals from non-professionals in Western society is difficult to break down. It is all too easy for professionals to assume the authoritative stance and families, in turn, take on the complementary role of patient or client waiting to be advised and directed by a person in power. The family's knowledge about the client is not shared, nor is the family's doubts about the workability of the plans explored. Families go away unable to assist their relative, the plan fails, and the family may be accused of sabotaging the treatment plan. Families and providers have much to learn about their habitual behaviors in a professional setting and even more about how to overcome them.

2. The laws of confidentiality in most states complicate the process of collaboration. it is a common belief of families that professionals use such laws primarily as an excuse for keeping families out of the way. This may be an accurate perception in some cases. It is incumbent on the part of providers, if they are not giving the information that the family wants, to be

completely honest with them as to why they are withholding it. They must make clear if they are doing so for legal for clinical reasons. They should know the state law on confidentiality well enough to explain to families its rationale and how it works. If providers have clinical reasons for keeping the family away, they should be honest enough to convey it to them.

It is unlikely that laws of confidentiality can be changed substantially without losing their capacity to protect client's right to privacy. It is up to skilled counselors to find ways of persuading clients that the support of their families is important and that families can be given essential information without jeopardizing highly personal information entrusted to the counselor.

Families relate that they are often victimized by the client or the system when the family has no idea what is going on. In order to protect themselves against such victimization, families need to take some firm stands in their own behalf. They could choose to refuse to pay bills for services they know little about. They may decide not to take a patient back home if they are given no information about diagnosis, treatment, and what to expect. Families should make clear to service agencies that they want to stay informed of emerging problems and if the client and agency decide otherwise, the agency must take responsibility for the next steps.

3. Another barrier to developing collaborative relations with families is our lack of understanding of the process of separation between family and client and our lack of resources and skill in making that transition a smooth one. Considerable tension between provider and family often occurs when the client makes his first move to community facilities. Families are accused of being "over-protective" and of "wanting to keep their relative dependent", and they are said to "sabotage treatment plans" when the client does not follow through on plans or when the family disagrees with the plans being made. There is need for a great deal more appreciation of the complexities of such situations and an avoidance of hasty conclusions and negative labeling.

some things to consider are the strong ambivalence that most clients have over the issue of independence and their capacities to make their families feel distressed and guilty for insisting that they live elsewhere. Families may also feel ambivalent about someone else taking responsibility for their relative after they have been solely responsible for him for many years, or the family may have had a number of experiences with failures of the system which makes it difficult to trust again. Providers need to understand the uniqueness of each situation and avoid the kinds of judgmentalism that result in tension and conflict.

There are other cultural factors that make the separation issue difficult to resolve. Our society gives mixed messages about the responsibility of one to care for one's dependent relatives. Undoubtedly many families have been made to feel guilty for keeping their relative at home by some providers and guilty for not being willing to do so by others. Families are often at the mercy of the provider's value system or, if the provider is young and has not resolved his own issues of independence from his parents, this becomes an added interference in his ability to work effectively with family-client separation issues.

4. Providers are often not prepared to handle the normal and inevitable conflicts that arise when they collaborate with families. It is in the nature of a conflict that all parties to it immediately begin thinking in terms of who is right and who is wrong and how to persuade the other to his point of view. It is important to recognize that in a collaborative model there can be no concept of right and wrong and that there is no stability in a resolution in which there are winners and losers. Providers need to learn medication skills in order that they know how to resolve conflicts constructively. Differences of opinion must be negotiated so that all go away feeling that their interests have been protected.

Families as Advocates for Rehabilitation Services

The need for a comprehensive community-based system of care and rehabilitation was fully documented by the President's Commission on Mental Health in 1978. Unfortunately, the Mental Health Systems Act which followed in 1980 was essentially nullified with a change of administration, and the federal government significantly reduced its commitment to those with severe mental illnesses. NAMI is now undertaking considerable research and study to determine for itself what the primary federal role in mental illness should be. While NAMI has been highly involved in essentially all legislation that has had a bearing on the well being of the mentally ill, it is now beginning to see the need to become more proactive and to develop a long-term legislative agenda of its own.

In order to responsibly devleop such an agenda, the organization is developing carefully conceived plans based on a comprehensive knowledge base. This involves such important steps as:

1. Directly involving persons with disabling mental illnesses and their families in research to identify their needs and the adequacy with which the system is meeting those needs.

2. Involving families and clients in the design of service delivery models and the study of options for funding, organizing, and delivering services.

3. Identifying the values, criteria, long-range needs, and measures of success that should guide public policy development related to mental illness.

4. Promoting through public education an understanding of mental illness, the importance of appropriate policy development to provide care for these people, and the need for funding and implementation of an enlightened system of services.

5. Developing the tools for evaluation and a plan for systematic and continuous evaluation of services to the mentally ill on local, state, and national levels.

Recognizing that no system of care is any better than the personnel who provide the service, a new advocacy effort is directed toward issues of selection, training, and retention of providers in mental illness. Given the labor intensive nature of the mental health system, it is critical that NAMI concern itself that we have adequately trained staff to meet the needs of the mentally ill. Robert Glover, Director of the Colorado Division of Mental Health, notes that over $8.3 billion per year is spent operating the public state mental health system na-

tion. More than 340,000 people staff these systems. (Glover, 1987). NAMI sees the need to direct its attention to all groups that influence how professionals are trained: professional organizations, academic institutions, state departments of human resources development, Education and Services Systems Liaison of the National Institute of Mental Health, and large employers. NAMI has now developed a committee structure that is beginning to organize itself for this difficult, but critical task.

NAMI is aware that advocacy can take many forms. NAMI members collectively spend hundreds of hours on the grass roots level serving watch dog functions as members of community service boards and hospital committees, and they spend countless hours studying budgets and lobbying their representatives on all levels of government. They have learned to influence the allocation of funds so as to ensure that the needs of those with the most serious mental disorders are addressed. In addition to these approaches, families are learning to use appeals procedures and to use the courts when no other remedies are forthcoming.

Conclusions

The first decade of NAMI's existence has been focused on its growth in membership, the creation of a sound structure to see it through the demanding road ahead, and establishing a sound financial base. Through these early years members have clarified their purposes and values and have articulated an ideological base that can be communicated clearly to others. NAMI has made considerable effort to educate its members about mental illness and the caregiving system, it has worked diligently against the stigma that has been entrenched in our society for so long, and it has tried not to lose sight of its first mission, that of giving comfort and support to patients and families devastated by serious mental illnesses.

Much energy has gone into advocacy on all levels of government. The coming decade will surely see a great leap forward in this area. What is significant is the reassessment of the whole caregiving system to which NAMI is committing itself. Advocacy will become much more sophisticated and much more clearly targeted when NAMI has had an opportunity to establish its own evaluation of how well services are working, to identify the unique needs of a diverse population of mentally ill people, and to add its own unique perspective to the design of programs and services.

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Excerpts of Reviews & Comments

The following are excerpts of reviews, comments and recommendations made by the 1988 Switzer Scholars. These are presented to further stimulate thinking, discussion and action as they relate to the content of "The Role of the Family in the Rehabilitation Process" by Agnes B. Hatfield, Ph.D.

As Dr. Agnes B. Hatfield states, a consumer movement such as the National Alliance for the Mentally Ill is long overdue. However, it probably could not have developed were it not for the shift in locus of treatment and care of the mentally ill from state mental hospitals to the community. When patients were bottled up inside "asylums" there was little opportunity for parents and concerned others to take hold.

The definition of what constitutes severe and long-term psychiatric disorder is, I agree, of great import to the kind of service system that will evolve. That it will be community-based rather than hospital focused almost goes without saying. What is not generally known is that the community mental health movement was actually predicated upon the concept of severe mental illness "as a mental health problem lying on a continuum ranging from the minor stresses of everyday living to the severe disturbances of schizophrenia," to use Hatfield's worlds. That may explain why the comprehensive community mental health center did not meet the needs of the severely mentally ill. Can a construct be devised that recognizes the new knowledge from biological psychiatry? Should this take the form of a rehabilitation program? Does the psychosocial educational model offer guidance? I think so, but there are some comments I'd like to make:

1. There is no training to speak of for any of the disciplines providing mental health/mental illness services that is preparing personnel to function in such a program. The big pushes of the 1970s to train community psychiatrists and community psychologists have pretty well simmered down. Transmittal of the newer psycho-biological knowledge is not yet incorporated in the community-based professional practice. Schools of social work are just beginning to show a flicker of interest in services to the long-term mentally ill; vocational rehabilitation counselor training has not moved much from orthopedics and mental retardation. New efforts are required.

2. To achieve the role of equal participation in treatment and rehabilitative services to which the National Alliance of the Mentally Ill aspires requires our turning to an earlier definition of rehabilitation, as a model of service rather than as a method. In that earlier construct rehabilitation involves a number of "team" players including roles for the client and his/her advocates, along with the professional and para-professional treaters, rehabilitators, and other service providers. The increasing popularity of rehabilitation carries the danger that it will be co-opted by one of the existing, less effective but more powerful disciplines.

3. Customers are just that--customers. They have the right to demand quality and to express the conditions that give them satisfaction. When they become involved directly in treatment and rehabilitation, they enter the provider role, for which they are not usually trained. In so saying I do not mean to denigrate the roles of understanding, supportive parent, relative, friend who can help make the environment more wholesome or healthy (not the same as therapeutic) for the ill person. Also, I do not intend to downplay the value of training for such roles.

4. "Self help" programs are of inestimable value, but we must not forget that there is an educational discipline involved in self help. None of the good programs with which I am familiar are haphazard. In self help, the adage about "the blind leading the blind" becomes modified to "the trained blind leading other blind." There's quite a difference.

-Bertram J. Black

This paper, "The Role of the Family in the Rehabilitation Process", focuses on the family roles in the process of rehabilitation. The National Alliance for the Mentally Ill (NAMI) is a collection of self help groups for families that has been cited as a powerful force for change in the care and treatment of the mentally ill; it serves as an advocate on the national level and a consultant on the state and local levels. This paper discusses the stigma, the differences between severity of the mental illness and its consequences; the family as a customer and their role in the rehabilitation process. There is also an emphasis on the family as a research source/expert in assessing the success of provided services. Hatfield raises concerns about the family and providers becoming collaborators.

This paper took a frank approach to the families' and service providers' roles and responsibilities in the rehabilitation process. However, I do not feel that the client should not be excluded. The family should continue to be an immeasurable source of information for research, yet the client as well as the service providers should be considered as sources of information in data collections. It is critical for 1. providing validity to the research, 2. identifying the unique needs of the mentally ill and family, 3. evaluating as to how the services work and designing of programs and services. The reviewer feels that people with long-term mental illness require comprehensive and continuous care which would be enhanced by a collaboration of the family, providers and client. This would warrant research to determine federal, local and state governments' roles.

-Jacquelyn Dickerson

The family movement has been very effective in the 1980s in getting family members around the country involved in many areas including lobbying, advocating, educating and securing funding. But there is a conflict with the consumer movement that seems to

be beginning to fester. The question is: do families speak for the patient? Are the wishes of the family members always the wishes of the patient-client-consumer, i.e. respecting commitment laws, etc.? The National Alliance for the Mentally Ill's Client Council seems to have no money to operate and little power in the NAMI superstructure with only one representative per state. Token consumerism needs to be avoided in the family members' movement. Consumers need to be recognized and treated as equal partners in the NAMI movement. NAMI needs to work in coalition with the national consumer organizations.

The issues that NAMI is facing has many implications:

1. Their emphasis on research is needed because in the past the National Institute of Mental Health (NIMH) research has been conducted along irrelevant lines. Also, medications are not sophisticated enough--too many side effects with possibilities developing for tardive dyskenesia and addiction. Also, the cause and cure of mental illness is still unknown.

2. Their emphasis on the difference between the seriously mentally ill and those people with mental health problems is important. The Federal Community Mental Health law was subverted and redirected to the "worried well." We have to be careful where new funds and resources are going.

-Christy Disher

Little needs to be said about the many contributions that the National Alliance of the Mentally Ill (NAMI) has made to the advancement of our understanding of the dynamics of mental illness and our efforts to help individuals overcome these illnesses. By allowing us to recognize the importance of using family members as partners in our work, we have opened up doors that have previously been closed. Old theories which place blame on family members and serve as a rationalization for excluding families from the rehabilitation process are a thing of the past largely due to the efforts of groups like NAMI. However, as the author suggests, one can still hear much talk about how families sabotage treatment. On the other side of it, families sometimes look at all professionals as being incompetent. It is clear that we need to continue to move in the direction of talking "to" each other as opposed to talking "about" each other. In order for this to happen agencies must set up a regular forum where consumers, families, and practitioners can talk to each other and develop service plans. Multiple family groups, open houses, conferences, and other events can promote a closer alliance between these groups. Training programs for mental health practitioners should include sessions on the philosophy of mental illness as described in this paper.

-Ralph Fasano

One of the main focuses of "The Role of the Family in the Rehabilitation Process" was the necessity for family members of the mentally ill to be directly involved in program development and training, as well as their right to be informed of essential information regarding the treatment of their relatives, a conviction widely espoused by the National Alliance for the Mentally Ill (NAMI). I am concerned, however, that the implicit goal of this "self-help organization" (i.e., family members helping family members) is somehow seen as working for the interests of the clients. NAMI is portrayed as the lay equivalent of a "professional organization for consumers," the service recipients, instead of a group founded to support and advocate for the interests of family members. NAMI's unique perspective is that of family members, not mental health clients, and the two viewpoints are not necessarily the same. The collaboration between families and providers that is discussed--based on a sense of equality, joint decision-making, and shared responsibility--would be complete (and more effective) were primary mental health consumers included.

In addition to their role as collaborators in mental health treatment and training, NAMI family members work as lobbyists to secure community resources for their relatives and to change laws which they see as ineffective or discriminatory. They advocate for more favorable legislation and resources regarding insurance coverage, disability payments, and research funds. NAMI itself has much to contribute to this psychiatric research due to its large and comprehensive knowledge base. NAMI has great strength and a powerful cause. Yet I would like to see them advocate **with** us, not **for** us, as we primary consumers are now speaking on our own behalf.

-Esso Leete

In this paper, Dr. Agnes B. Hatfield focuses on critical issues in the role of the family movement that have far-reaching consequences for conceptualizing the parameters of mental illness and the rehabilitation of people with mental illness. The influence of the National Alliance for the Mentally Ill (NAMI) is epistemological as well as political. It is important to point out that in both family movements that have affected scientific theory and practice--the National Society for Autistic Children as well as NAMI--there was a meshing of research developments with the experiential convictions of families that these types of disorders were, in fact, organically based rather than psychogenic. It was easy to attribute these parental convictions to defensiveness and self-absolution. But they were based on a data source absolutely unavailable to professionals--lifetime observations of the developmental course of the illnesses and longitudinal comparisons with other children in the same rearing environment.

Hatfield's paper makes an important point: "mental illness" may be less pejorative than a "mental health problem" if it is viewed by society as biologically-based. As in the case of chronic physical and developmental disabilities, this variety similarly requires rehabilitative efforts to overcome deficits in learning and function. The rehabilitation model, it seems in-

creasingly evident, may be a more effective tool than psychotherapy in addressing the psychological sequelae of the so-called mental disorders. Negative symptoms of schizophrenia, such as withdrawal, amotivation, and anhedonia may be based to some extent on biological factors (avoidance of overstimulation), but they are also psychological responses to societal devaluation. Rehabilitation efforts that build competencies and social skills provide a surer route to self-esteem than intrapsychic exploration, particularly in persons with core deficits in processing reality.

Families generally agree that the two most important elements in patient stabilization and progress are psychotropic medications and these skill-building and resocialization technologies. Distinctions between treatment and rehabilitation seem irrelevant. In point of fact, when one looks at the psychosocial component of treatment, i.e., individual or group psychotherapy, there is a label frequently attached to supportive counseling or group meetings which in no way meet classic definitions of psychotherapy. "Therapy," "counseling," and "psychosocial rehabilitation" are often terms which are connected with the credentials of the mental health professional administering them, tied in with medicaid and medicare reimbursements rather than with substantive differences in struture and function. It might be best to get away from the notion of therapy altogether, which implies an attempt to cure the basic psychopathology. Since all our treatments have to do with restoration of function, including chemotherapy, rehabilitation is undoubtedly the better term.

It is a sad reality, however, that our aftercare programs are filled with professionals who have been trained only as psychotherapists or as psychodynamic counselors, and who make procrustean attempts to mesh their skills with clients who need rehabilitative rather than intrapsychic interventions. There is clearly a need in our clinical training programs for curricula with content and technologies that focus on the seriously mentally ill population. It is here that families have a vital role in advocacy. As Hatfield has indicated, families need to make sure that the professionals who treat their family members are knowledgeable about current, empirically-tested theory and practice, and this certainly includes rehabilitation technology. Advocacy with regulatory bodies and state legislatures to ensure a focus on rehabilitation in aftercare facilities and in publicly-funded clinical education, with demonstrated commitments to state-of-the-art professional training, can be extremely important role for AMI families.

The estimate (from the best possible source) that only 15 percent of seriously mentally ill persons in the community are participating in any of these organized programs is of great interest. As hatfield suggests, NAMI families are a fertile subject pool for answering a large number of questions relevant to service untilization and evaluation of existing programs. However, we are all agreed that NAMI families are a skewed sample of the universe of families of the mentally ill; they are predominantly white, middle-class, and well educated. For purposes of this discussion they may offer a "best case" example of the ways in which educated and relatively economically secure families help mentally ill members develop coping skills. The majority of mentally ill persons are not, however, in this category; diagnoses of schizophrenia and hospital admissions are overrepresented among the poor and specific minority groups (Dohrenwend, 1980; National Institute of Mental Health, 1987).

NAMI families, however, may provide clues to the important issue Hatfield has raised with respect to a subset of mentally ill persons who do not want to enter the client world. This is a very different group from the young adult chronic patients, whose approach-avoidance posture toward the system varies according to temporary need. These are persons who do take care of their illness but do not want to be identified by it or with it. Impressionistically, they seem to be divided into two types: a small number who are quite functional and with medication seem to be able to do without the mental health system, and a much larger number who would benefit greatly from a program but rely on their families and/or sometimes a private therapist for their social sustenance. Able to live on their own, but lacking peer supports, they lead empty lives because they are too functional for most day treatment programs but too dysfunctional to work or make friends in a mainstream environment. Some programs are now being developed for this group, e.g., the continuing education program developed by the Center for Psychiatric Rehabilitation at Boston University, but in the main the system has little to offer them. It is here that primary consumer-run programs, offering productive roles and peer supports outside of the mental health system, can become the best type of rehabilitation modality. Persons who consider it stigmatizing to be "ex-mental patients" may change their minds when they see well-functioning individuals, many with professions or advanced degrees, who openly acknowledge this identification.

In contrast to primary consumers, who may provide the best vehicle for social rehabilitation, families must tread a fine line between helping the system and relieving the system of responsibility. As Hatfield notes, families are an untapped resource of information about program effectiveness and client satisfaction. NAMI families have also been involved in developing and in some cases, managing a range of rehabilitation alternatives, including housing, psychosocial rehabilitation programs, and sheltered workshops, designed to fill gaps or supplement inadequate resources in the service delivery system. Many of us believe that resource development is a praiseworthy but inappropriate function for families. It tends to relieve government of accountability and may reinforce a differential system of care based on family investment of time, effort, and money. Families have a much more appropriate function as adjunctive aids to the system on both case-centered and societal levels. There are important roles for family members in program evaluation, monitoring, mental health systems planning, and--based on assessment of needs and program efficacy, educated advocacy for the

most cost-effective use of tax dollars for people with mental illness. Together with primary consumers, families also constitute an invaluable educational resource for clinicians at all levels of training: preservice, in-service, continuing education, and individual case conferences. Families are experts on their relatives' level of functioning, longitudinal progress, and specific variables relevant to psychiatric rehabilitation. As a group, they are the best single source of data for evaluating the goodness-of-fit between that which is required and that which is offered by the service delivery system and by the educational system which prepares practitioners to meet its needs.

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-Harriet P. Lefley

I have recently heard a psychologist state at a rehabilitation counselor training workshop that when a person with chronic mental illness comes home from the hospital, his mom is probably responsible for getting him to stop taking his medication. My concern is not only for the offensive, blaming messages being sent by this one man, but for the many like him who I fear are out there "training" rehabilitation personnel. Hatfield writes eloquently of the National Alliance of the Mentally Ill's (NAMI) progress in advocating for the needs of persons who have severe psychiatric disabilities. However, the need for NAMI to participate in the education and training of rehabilitation professionals is great. While I would like to agree with Hatfield that, as regards families, "traditional deference to any statement made by someone with a professional degree has largely vanished," I am not sure that I can. In teaching families coping skills, I have found that parents, sisters, and in-laws are frequently intimidated by professionals and too often are unwilling to demand that their needs be met, or that the needs of their ill relative be met.

Hatfield, in a previous work, has referred to families working together as a "skills exchange." In this paper, she suggests that "many families have inadvertently developed ways of doing things that might be emulated by professional rehabilitation services." I have found this to be true whenever I have brought families together in a structured skills training, or when I have brought families together to speak to future professionals. Unfortunately, I have found that families who are willing to address the legislature may be timid when it comes to addressing graduate students in rehabilitation counseling. Thus, while one or two family members may be willing to speak in university settings, educators should encourage all members of NAMI to bring their voices to the classroom. Further, I would like to encourage NAMI as it develops its "long-term legislative agenda" to share the knowledge they have gained, not only with the general public, but with professionals-in-training, and with practicing professionals through continuing education. Certified rehabilitation counselors, for example, are required to participate in continuing education. NAMI should take an active role to ensure that the training practitioners receive acknowledges the role of the family in the rehabilitation process.

-Catherine A. Marshall

The National Alliance for the Mentally Ill (NAMI) has been instrumental in effecting meaningful legislative changes through the years. Parents and families of persons with psychiatric disabilities must have a voice in the treatment and vocational planning of their loved one. This must be done jointly with professionals in the mental health and rehabilitation fields. Care must be taken not to smother the person as can sometimes happen.

Of special concern to me are people without caring family members or without a family. They have little if any support system to rely on. Who will advocate for them? Who will walk through the strange and threatening rehabilitation or mental health maze with them. A need is seen for adequate training for mental health and rehabilitation professionals so they can more adequately address the needs of people with psychiatric disabilities who have no support system. These are often the people with little, if any, work record, several failed attempts with vocational rehabilitation, and numerous hospitalizations. A SSI check or SSDI check without adequate support will only aggravate the situation. Steps must be taken to reverse this trend so people can avoid being lost and/or forgotten. Many wind up in prison as their only support group leads them to crime.

-Robert J. Neuman

Dr. Agnes B. Hatfield has written an exceptionally thoughtful, incisive paper that discusses not only the role of families in rehabilitation, but the history and objectives of the National Alliance for the Mentally Ill (NAMI), the need for creative approaches to providing rehabilitation services, and the role of families as advocates. I would like to comment on three specific areas that I believe will affect rehabilitation in the 1990s 1. research, 2. clienthood, and 3. advocacy.

Research

In my discussion of Dr. William A. Anthony's paper, I remarked on the need for a balanced research agenda. As Dr. Hatfield noted, biological research on the brain had long been neglected. However, a combination of significant advances in technology, which have made it possible to conduct biological research, and the political support of groups such as NAMI have significantly increased resources and attention toward biomedical research. My concern is that services research is not receiving the same needed atten-

tion. As some are beginning to point out, it is becoming increasingly more difficult to fund research that does not have a biological base (Goode, 1988).

We are all extremely hopeful that biomedical research will reveal the causes and find a cure for the major mental disorders such as schizophrenia. In the meantime, approximately $15.7 billion is spent each year on services and supports for people with long-term, severe mental illness (Sharfstein in House Report, 1988), much of it supporting ineffective services (House Report, 1988). Many hundreds of thousands of people continue to lack the services and supports needed to live decent lives in the community. As I discussed in my reactions to Dr. Anthony's paper, I believe we urgently need credible data to improve the way existing resources are used and to influence decision-makers to allocate additional resources. These data can only be generated through carefully designed and conducted community support and rehabilitation services research, and service demonstration and evaluation projects. If rehabilitation is going to advance into the 1990s and if programs are going to survive, the field will need a balanced research agenda that supports services research as well as biomedical research.

Clienthood

I strongly concur with Dr. Hatfield's concern about socializing people with mental disorders into the formal system and a lifelong preoccupation with mental illness. I made a similar point in my reaction to Dr. Anthony's paper regarding the need to change our assumptions about people with mental disorders. I would like to see this reflected in our themes for rehabilitation in the 1990s. However, I recognize that this will be a major challenge for us in the mental health field. We have expended enormous time and resources to build expertise in providing professional services and in developing operating programs such as clubhouses. It will not be easy to acknowledge that a "recreation center" or "adult education class" could be as effective, or more so, than our established programs.

I think we need to keep two things in mind. First, in accordance with rehabilitation values, client preference must be foremost in service decisions. If clients prefer museums, college settings, and ordinary work places, the service system must do everything possible to help that person succeed in that setting. Secondly, given the prevalence of mental disorders, an increasingly unstable society, and the growing incidence of substance abuse, there will certainly be clients who prefer to remain and benefit from receipt of services within the formal system, either temporarily or long term. However, the more individuals who can be helped to use the less formal, less costly supports, the more resources will be available for those who may need more intensive care.

Advocacy

Although I addressed the importance of advocacy in my reactions to Dr. Anthony's paper, I would like to reiterate how critical I believe advocacy is to increasing effective rehabilitation services. The sweeping reform of the public mental health system that resulted in the passage and implementation of the Community Mental Health Center Act of 1963 was a direct result of a coalition of mental health interests, graphically illustrating the power of coalitions (Rochefort, 1987). The changes that occurred in the Wisconsin mental health system have been attributed to the persistent efforts of the families.

However, to advocate effectively, it is important to know what to advocate for. Therefore, I believe families must become as knowledgeable as possible regarding effective service approaches and, with this information, become involved in all state and local mental health planning processes.

Conclusion

It was a pleasure to read Dr. Hatfield's paper. Clearly, families play a key role in the rehabilitation process but can also be critical to the expansion and refinement of rehabilitation services in the next decade through their advocacy efforts to increase resources for services and supports to maximize the independent living and recovery of their relatives.

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-Jacqueline Parrish

Dr. Agnes B. Hatfield succinctly provided an overview of the development of the family movement, specifically the National Alliance for the Mentally Ill (NAMI), during the past decade. NAMI's primary mission is to give comfort and support to consumers and families. Initially it focused on its own institutional concerns, that is membership growth, organizational structure and funding. Its energies are currently focused on education of its members and mental health providers, advocacy, and research on need identification, service evaluation, and program design. Hatfield questioned how best to conceptualize and define mental illness, and pointed out the importance of recent developments of brain research and understanding biological processes. After touching on the consumer and self-help movement, she described at length the family's involvement in psychiatric rehabilitation.

The author in discussing the definition of mental illness, makes the point that how a problem is defined makes a difference to those affected by it. It would have been helpful for her to give more details as to what she meant when stating that "NAMI members believe that if mental illness separates itself from mental health, it can have profound consequences. . . ."

Hatfield's acknowledgement of the need for families to act as collaborators with professionals in psychiatric rehabilitation is pertinent. The challenge lays in defining and implementing such collaboration. Professionals

too long have been indoctrinated in their role of allegiance and loyalty to the patient versus the family. NAMI would be in an excellent position to develop and implement educational programs to use with consumers, families and caregivers to overcome the resistance and potential conflict within this collaboration. Collaboration models, communication techniques, role definitions, confidentiality issues, etc. should be addressed.

-Carole Schauer

In this paper, Dr. Agnes B. Hatfield discusses three primary roles which families play in the psychiatric rehabilitation process after reviewing the purpose and ideology of the National Alliance for the Mentally Ill (NAMI) to which a growing number of families with mentally ill relatives belong.

NAMI was founded less than 10 years ago and has grown to over 8,000 members nationwide. The ideology of self-help is a guiding principle of the organization; and it has become the lay equivalent of a professional organization for families who define themselves as mental health consumers ("Secondary Consumers" in contrast with direct recipients of mental health services who define themselves as "primary consumers".) As such NAMI has increased media attention to mental illness; successfully lobbied for increased funding for services; vigorously participated in the debates dominating the field regarding theories of mental illness, the kind of research to be done and the way in which services are delivered. This families' organization believes that social planners, academic institutions which educate professionals to work with people with mental illness, and service providers must incorporate the NAMI perspective into their work to assure relevancy of service delivery.

Though the organization places great credence in the biological basis for schizophrenia, supports "brain" research, and highly values medication as a treatment for this "physical" illness, it nevertheless is fully aware of the negative symptoms of the disease (low motivation and social withdrawal) for which rehabilitative processes are currently the only reliable treatment.

Rehabilitation defined as "remediating disabilities and compensating for handicaps" involves two types of interventions:

1. Patient skill development and

2. Environmental resource development.

Families thus fulfill three primary roles:

As Agents of Rehabilitation

Because small percentages of people with serious mental illnesses participate in community programs, large numbers of families are themselves striving to create environments conducive to their relatives' development. Hatfield concludes that more "mainstream" models of socialization where clients have a wider array of role models from which to choose; and an array of places (other than clubhouses, community rehabilitation centers and therapeutic residential care) such as museums, adult education classes, theaters, etc. would be most beneficial.

As Collaborators in Rehabilitation

Though there are barriers to this collaborative relationship such as hierarchial roles professional versus non-professional laws of confidentiality, lack of understanding of the process of separation between family and client, lack of preparation by professionals to mediate the normal and inevitable conflicts which arise; these must be overcome to involve families as equal partners in the decision-making processes.

As Advocates for Rehabilitation Services

Though NAMI has been involved in all past legislative efforts which focused on mental illness, it is now developing its own legislative agenda. Additionally it is advocating for adequately trained staff in rehabilitation models and intends to influence the allocation of funds to ensure that research, training and ultimately the service needs of those with the most serious mental disorders are adequately addressed.

-Marye L. Thomas

Summary of Recommendations on the Family's Role in Rehabilitation

The following is a summary of the Recommendations for action developed by the 1988 Switzer Scholars as they relate to "The Role of the Family in the Rehabilitation Process" by Agnes B. Hatfield.

I. Recommendations for Research:

1. More research is needed to describe how families cope when there is a mentally ill member. We need to know about the special problems experienced by spouses of mentally ill persons, as well as about siblings and about children who are caring for mentally ill parents. The impact of mental illness on the economic condition of the family, the health and safety of members, and the stress on marriages needs to be better understood.

2. Study the various coping styles of families with particular emphasis on highly effective strategies.

3. Learn more about minorities and disadvantaged people and how they cope with mental illness, what their special needs are, and how they might be brought into the family movement. We need to know about mental illness in jails and prisons in order to be effective advocates in their behalf.

4. A range of intervention studies is needed in which consumers and families determine how well various services are working. These include respite care for families, various kinds of housing services, and rehabilitation. We especially need to know how well the revised vocational rehabilitation (the 1987 amendments) legislation is working.

5. There is considerable concern for the large number of persons with mental illness who are not in the service system. The needs and concerns of this group are not reflected in most research. The National Alliance for the Mentally Ill (NAMI) could be a good resource for studying this neglected group, since families know of their existence even when the service system does not. Consumer groups may also know of members who are not in any part of the caregiving system.

II. Recommendations for Policy and Program Development:

1. Schizophrenia and affective disorders are physical illness and should be treated equitably with all other physical illness in relation to medical insurance and life insurance.

2. There should be non-discrimination protection for people with mental illness in housing, work, drivers' licenses, and all forms of insurance.

3. A variety of affordable housing options should be available which would include apartments, group homes, and independent living with personal care provision. Various levels of intensity of support should be provided to meet the range of needs. Families should be reimbursed for care when the person lives at home.

4. Families should receive from providers all the information needed for them to fulfill their role as care providers. Laws of confidentiality should not be construed so as to keep from families pertinent information needed to provide safe and effective care. Families should be told their rights and responsibilities, and should be referred to available support groups and community resources. The decision as to whether the ill person is to return to the family to live is a matter for the family and consumer to decide.

III. Recommendations for Training:

1. The quality of personnel is by far the most important factor in successful programs for consumers. Make sure that professional training programs are current in terms of the biological basis of mental illness and the roles of medication and rehabilitation in treatment. Professionals need to understand the personal side of having a mental illness and the family experience in having a member become mentally ill. Training institutions should bring consumers and families into their classes to provide first person accounts of these experiences

2. The states need to play a strong role in influencing training. They are employers of large numbers of professionals and should set high standards for employment. States should encourage state universities to serve the public in its need for better training in mental illness. States might offer stipends for students in this field and require that they serve in the public sector as a way to pay the state back for its investment. The state might have to establish special training institutes in mental illness for continuing education. They may need to create special certification in mental illness. Vocational rehabilitation counselors must be mandated to have training in mental illness.

IV. Recommendations for Legislation:

1. Legislation is needed to ensure proper and adequate funding for supportive work initiatives and other rehabilitation services, for badly needed outreach programs to consumers that do not seek services, and for affordable housing.

2. Persons with a mental illness must be covered by any catastrophic health insurance or home health care legislation.

3. People with mental illness must have equity in civil rights protection with all other people and be covered under the law. There must also be enforcement of affirmative action for the target group under the provisions of affirmative action for all people with disabilities.

V. Alleviating Stigma

Stigmatizing of people with mental illness is a serious problem in our society and unfairly punishes people for having an illness. This problem needs to be studied in order to better understand all the forces in our society that maintain this tragic state of affairs. This means increased attention to the media, public education, and professional education. Mental illness needs to be de-mythologized, and the public needs to get to know people with these disorders by participating in such approaches as programs without walls. We also need to be sensitive to language that we use and tendencies to label so that we don't inadvertently add to stigma.

Special Invited Paper

Self-Help Movement of Consumers of Mental Health Services

Christy Disher

The self-help movement of past and present mental health consumers in the United States began 30 to 40 years ago. It developed in response to the abysmal conditions in hospitals, the violations of personal rights, the dehumanizing treatment such as restraints, unwarranted seclusion, over-medication or incorrect medication and generally being treated like second-class citizens by professional and the public alike. Patients found compassion and strength by joining together and sharing their struggles, as is common in all self-help groups.

Christy Disher is First Vice President at the National Mental Health Consumers Association, and the Director of "On Our Own" of Montgomery County, Maryland.

As expressed in a fact sheet distributed by the National Mental Health Consumers' Association (NMHCA), "Self-help groups of mental health consumers typically provide emotional support and a variety of forms of practical help for dealing with problems that are common to all members. Such groups counter the feelings of loneliness, rejection, discrimination and frustration common to mental health consumers by offering mutual support, companionship, empathy and sharing." Participating in self-help groups is an empowering experience for one whose life has been shattered by a series of hospitalizations and rejections. One of the benefits that occurs in a self-help group is the sense of community and belonging one receives. This is particularly important for mental health consumers who tend to be withdrawn, isolated and without friends. In a self-help group all are equal or peers, unlike the doctor-patient relationship. The NMHCA fact sheet describes some of the basic values of consumer-run services. "First is freedom of choice. Only the consumer decides whether to participate. . . . Consumer control is another basic value. All decisions regarding services and governance of the organization are made by consumers." Members of the group contribute what they do best to the group and there is a feeling of accomplishment and satisfaction in helping another as well as being helped. The result is an increase in self-confidence so important in the recovery process. Another way for members to increase self-confidence is to practice social skills in a safe environment. Sue Estroff, Ph.D., states in a recent paper entitled, "The Next Step: Self-Help" that "it is time to make good on the often forgotten but fundamental premise and promise of deinstitutionalization--the realignment of power, control and responsibility among the givers and receivers of treatment." More and more jurisdictions are realizing that consumers of mental health services can also be providers.

One of the first self-help groups of mental health consumers was "We Are Not Alone" that developed into the now famous Fountain House in New York City. The self-help movement is rich in diversity.

Groups sprang out of Mental Health Associations, out of the family movement and out of the liberation movement. At first there was a small number of groups, mainly in the large cities. There was a big spurt of growth about nine years ago

mainly because of the Community Support Program of the National Institute of Mental Health and its philosophy to encourage natural support systems. The self-help movement culminated three years ago with the formation of the National Mental Health Consumers' Association which will be discussed later in this paper.

An example of a self-help group is, "On Our Own of Montgomery County, Inc." in Rockville, Maryland. On Our Own operates a drop-in center which is a house open evenings and weekends for informal socializing. (These are the times when people tend to feel lonely and disconnected.) On Our Own's goals are mutual support, socialization and advocacy. There are member-run Rap Sessions, member-run workshops, guest speakers and some of the members involve themselves at the local, state and national levels with advocating for the rights and needs of people with mental illness. On Our Own of Montgomery County, MD, will celebrate its fifth anniversary this year.

Other types of consumer-run services include residential services, crises intervention, vocational services and case management services. Another example of consumer-run service is "Project Overcome" in Minnesota. The consumers in this group formed a speaker's bureau to combat the stigma of mental illness. They speak to community groups about their experience with the illness and present a positive image to the public. "Our Turn" in Washington, D.C., sponsors a coffee house and laundromat to help the homeless. Many states have organized a statewide consumer network to advocate more effectively. On Our Own of Maryland has taken positions against a relaxation of inpatient and outpatient commitment standards.

With the burgeoning of local and statewide groups across the United States, there was a call in 1985 for a national organization of mental health consumers. In the ensuing couple of years there was much interest, activity and argument as to what form this organization would take. In the summer of 1987 a constitution was drawn up at the third national consumer conference sponsored by the National Institute of Mental Health. This was the birth of the National Mental Health Consumers' Association. Some of the goals of the NMHCA include protecting the rights of all consumers, creating more consumer-run alternative programs, ending discrimination in housing and employment, fighting stigma and having more consumer representation on mental health decision-making bodies. This is a tall order to fill but much as been done already toward these goals. The NMHCA, which is based in Philadelphia, has helped many local groups, built coalitions with other advocacy groups, helped develop and monitor the new Protection and Advocacy federal legislation, testified before Congress and tried to educate the media with positive portrayals of patients.

It is probably everyone's wish who is involved in this great movement that personalities, philosophical differences and egos be put aside to achieve unity so that some basic human goals for those suffering can be accomplished. More and more self-help consumer-run programs are being accepted as a necessary and vital link in the community support services. The voices of patients and ex-patients in the United States can no longer be ignored. Consumer-run enterprises should be encouraged, supported and funded in every community in the United States and abroad. The benefits far outweigh the usually modest cost, and those consumer-run services that already exist demonstrate their effectiveness.

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Gallaudet President I. King Jordan 's welcoming remarks to the 1988 Switzer Scholars were in voice as well as sign language. Gallaudet University graciously hosted the seminar at its Washington D.C. campus.

Special Invited Paper

Service Needs of Mentally Ill Deaf Persons

Carole Schauer

Historically, deaf persons seeking mental health services have been confronted with service providers lacking knowledge about the special considerations related to hearing impairment. Inappropriate evaluation, inaccurate diagnosis, superficial treatment and/or denial of service are often the norm. Services geared especially for mentally ill deaf persons exist on a continuum of sporadic and scattered service components to the total absence of accessible services.

Statistics on the number of persons who are deaf in the United States vary considerably. Based on estimates of hearing impairment from the Health Interview Survey conducted by the National Center for Health Statistics, 21.2 million persons in 1985 were hearing impaired in the United States (Hotchkiss, 1987). Additionally, persons were asked to report themselves when deaf in both ears. Based on the 1977 sample, it was estimated that 346,000 persons in 1985 would have reported themselves as "deaf." This estimate of numbers of deaf persons is more conservative than a 1981 calculation (using the work of Schein and Delk) of 2.3 million persons having severe-profound deafness (Heller, 1981.)

Estimates of the total number of deaf persons needing mental health services are even more unclear and diverse because of insufficient empirical information. Research in the early 1960s demonstrated that types of psychotic illness were the same for deaf patients as for hearing patients (Rainer, et. al, 1963); however, other studies have shown this rate to be higher. The few studies on severe mental health problems in deaf children indicate a prevalence of between eight percent and 22 percent of the population (Heller, 1981). Heller, assuming that hearing impaired children have emotional problems at twice the rate of hearing children, and that adults have no less mental health problems than the general population, hypothesizes that about 20 percent of the hearing impaired population or 468,000 severe-profound deaf persons suffer mental disorders. If this 20 percent were applied to the 346,000 deaf persons from the National Center for Health Statistics, only 69,000 would have mental disorders.

A survey of hearing impaired patients in 282 public psychiatric hospitals throughout the United States in 1982 found 13,401 persons, or 9.4 percent to be hearing impaired or 94 per 1,000 of the total hospital population. Of that number 79.5 per 1,000 were hard-of-hearing and 13.5 per 1,000 were deaf (Trybus, 1983). The study demonstrated that more than one-third of the hearing impaired patients had a hospital stay greater than 10 years. Also, whereas one-third of the patients in general had hospital stays of less than six months, only 12 percent of hearing impaired patients had corresponding stays.

While the numbers of deaf persons with mental illness may not be clear, it is widely known that these persons are under-

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served, and that nationally, huge gaps exist in mental health service provision portraying a service system anywhere from one to three decades behind. Presently, there are probably no more than 25 to 35 inpatient units, 30 to 40 outpatient units, and a dozen group homes for mentally ill deaf persons in this country (Trybus and Edelstein, Long). Statistics on Community based psychosocial services are unavailable, but it would be safe to predict that such services are few and far between.

Currently, mental health systems are still struggling to establish both inpatient and outpatient treatment services for deaf persons at a time when the national trend is for deinstitutionalization and for providing an array of community-based programs with consumer and family involvement. Program developers as well as administrators of existing programs for mentally ill deaf persons must give special attention to developing community-based mental health services, including crisis stabilization, case management services, a continuum of residential services, socialization and vocational programs, and self-help consumer groups. Such services not only address the needs related to mental illness, but have important ramifications for addressing communication and socialization needs related to isolation which is a significant issue for mentally ill deaf persons.

Deafness is a handicap of communication. Deaf people have the same psychological needs as others. Deafness does not alter a person's need for love, acceptance, productivity, and independence. Deaf persons are often underestimated by the general "hearing" population because of the existing communication barrier and because of the lack of understanding of deafness. The long-term mentally ill deaf person faces exceptional difficulties in coping with one's illness, in developing personal resources to secure the basic necessities of life, and in finding accessible quality program services.

Accessibility to services for deaf persons demands:

1. fluent skills in sign language and knowledge of psychosocial aspects of deafness by service providers, and

2. physical accommodations such as teletypewriter devices for telephone communication; flashing signal lights for phone, smoke detection, and doorbells; decoders, etc.

Goulder estimates that no more that 20 states in this country have both public and private programs for inpatient and/or outpatient services for deaf persons (Goulder, 1988.) To meet the paucity of services in this country, each state either through legislation or executive order must mandate the development and implementation of comprehensive psychiatric rehabilitation services for mentally ill deaf persons. Deaf persons must be included in the planning, development and implementation of such services. Special consideration must be given to affirmative action policies in recruiting and hiring deaf persons for administrative, professional and line staff positions. Institutional programs often face great difficulty in meeting this policy because of the absence of deaf persons within medical and nursing professions; however, deaf psychologists and social workers can be found, although in limited number.

Qualifications for employment in such programs must first address the need for fluency in sign language and knowledge in psychosocial aspects of deafness. If qualified applicants cannot be found, then persons hired must be sensitive to the needs of deaf persons and be willing to undergo intensive training in both sign language and psychosocial aspects of deafness.

Community based psychosocial programs, because their staff positions are more generalist in nature, have greater opportunities to hire deaf persons, particularly from the fields of social work, counseling, education and psychology. Inservice training needs for this group generally include such topics as diagnostic categories of mental disorders, communication and behavior techniques, actions and side effects of medication, the psychosocial rehabilitation approach and necessary service components, case management practice, and consumer and family issues. Case management has become extremely critical in serving deaf persons with mental illness because of the multiplicity of their needs and the inaccessibility of general community resources and social service programs.

Qualified sign language interpreter services, both staff and contracted, are critical for successful programming and must be included as a priority item within the budget. Not only do interpreter services ensure access of services to patients, such services especially permit deaf staff to function as equal partners in the treatment or service team.

In conclusion, certainly persons with both mental illness and deafness deserve as much opportunity to find relief from their illness as their hearing counterparts. Public and private service systems must begin to address accessibility issues and develop and implement programs geared to this population. More importantly, priority status must be given to establishing strong outpatient services and an array of community-based programs.

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Special Invited Paper

Some Ideas for Positive Change

Jacqueline Parrish

"Rehabilitation Programs in the 1980s: Laying the Groundwork for the 1990s" by Dr. William A. Anthony radiates positive expectations about client potential, a positive vision of looking forward away from the problems of deinstitutionalization (a valid and humane movement implemented in a narrow, negligent manner) towards community integration through effective rehabilitation, hope, client-centered values, and concern for the needs of families.

As Program Director for the National Institute on Mental Health (NIMH) Community Support Program (CSP), I would like to add my perspective to Dr. Anthony's paper. He has provided us with the vision for the future. I would like to address what is holding us back from realizing that vision and what are some policy, program, training, research, and legislative strategies that could move us forward, so that by the end of 1990s, there would be services and supports in every locality based on the values and philosophy presented at the end of Dr. Anthony's paper.

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Although, as 1988 Switzer Scholar Dr. William A. Anthony points out, there is a growing knowledge base on the effectiveness of rehabilitation services for helping people with severe mental disorders to live, learn, work, and socialize in the normal community environment, there continues to be insufficient support for the proliferation of such approaches, which has resulted in hundreds of thousands of neglected individuals around the nation. This is clearly evidenced by the 1. continuing undue burden placed on the families of clients, and 2. the excessive use of costly hospitalization, 3. the repeated encounters by people with mental disorders within the criminal justice system, and most devastating of all, 4. the growing number of homeless mentally ill persons.

Specifically, of the estimated 1.5 to 2 million adults with severe mental disabilities, approximately 800,000 live with their families (Torrey, 1986); 25 percent of all hospital days are for mental illness (Merwin & Ochberg, 1983); according to the National Coalition for Jail Reform, there are approximately 700,000 incarcerations of people with severe mental disorders each year in jails and prisons, and shelters which now house between 150,000 and 300,000 people with severe mental disorders (Paterson & Craig, 1985; Torrey & Wolfe, 1986), are increasing each year.

The main obstacles impeding increased development are:

- Unsubstantiated assumptions about the client population--there continues to be widely held beliefs, within the traditional mental health field, as well as the general public, that people with severe mental disorders cannot recover, i.e., can never live, work, and function effectively in the community. These assumptions have fostered the continued use of ineffective services, thwarted public support for increased resources, discouraged mental health professionals from working with the client population, and undermined clients' self-esteem, sense of hope, and potential for growth and change.
- There is a growing body of evidence that people can recover, change behaviors, improve functioning, and learn to manage their symptoms (Straus, et al, 1985). For example, the Vermont Longitudinal Study, one of the few long-term studies conducted on the client population, followed a group of extremely disabled clients and found that after five to seven years, a majority began to recover,

and at the 20-year mark, two-thirds were living productive and involved lives in the community with few symptoms and service needs (Harding et al., 1984). As 1988 Switzer Scholar Dr. Agnes B. Hatfield points out in her paper, many people with severe mental disorders never enter the mental health system at all. Instead, they use alternatives such as the clergy and medical doctors (Horwitz, 1987) and appear to successfully manage their lives.

- There is, therefore, increasing evidence that many people with severe mental disorders can recover and rehabilitation approaches are helping people to do so. Yet the attitude that they cannot recover or function without long-term services prevails and results in continued support for programs that foster dependency, the patient role, and maintain them as long-term service users.
- Lack of resources to develop services because a substantial portion of the resources potentially available are used to fund institutional care--As recently noted by Congress, most of the client population now receive few services, primarily because the bulk of public funds are "being spent poorly and frequently in the wrong places". (House Report, 1988, p.12) Mental hospitals continue to consume almost 70 percent of state mental health budgets (Alpha Centerpiece, 1986; Kiesler, 1982), yet serve less than one-sixth as many persons as do community mental health centers (CMHCs) and other related services (Goldman & Manderscheid, 1987). Some hospitals are providing improved acute care but at a disproportionately increased cost because of reduced patient census. For example, in New York, as the patient census dropped from 93,000 to 24,000, the number of hospital staff increased from 23,800 to 37,000. (Torrey & Wolfe, 1986)
- Lack of qualified staff to provide community rehabilitation services--Although research and program experience have clearly demonstrated the importance of providing services in the community and assisting clients to learn and to use community living skills (Brekke & Test, 1987; Merwin & Ochberg), schools of medicine, social work, nursing, and rehabilitation counseling have not altered their curricula, which emphasize acute illness, office-based services, and psychotherapy and are, therefore, not producing professionals with the skills and attitudes needed to work with the client population. In addition, people are not being attracted to work in rehabilitation programs for the client population, because of low salaries, benefits, and status.
- Continuing adherence to a narrow medical model viewpoint--Anthony makes the excellent point that rehabilitation was never meant to replace treatment but rather complement it, since each approach meets different critical needs. Unfortunately, there continues (as brought to our attention at the national level at conferences and planning meetings) a reluctance within the medical establishment, which has traditionally been responsible for the care and treatment of people with severe mental disorders, to adopt newer models that alter basic beliefs and approaches. These newer models focus on health rather than disease; growth rather than maintenance; a rehabilitation approach that includes a broad array of services and supports rather than heavy reliance on drug solutions; and staff roles in which the case manager may be more central to a client's well-being than the psychiatrist. Clearly, the biological approach toward mental disorders helps to control symptoms; however, it does not help clients deal with major life problems or achievement of their goals and potentials. (Goode, 1988; Mosher, 1986)Although, as Anthony points out, rehabilitation is an essential complement for medical treatment, these services do not command comparable financial support. Many community rehabilitation programs struggle to survive despite growing evidence of their effectiveness. (Anthony & Dion, 1986) On the other hand, considerable support continues for medical-based approaches, as reflected in professional training programs, preferred practitioner approaches (Mowbray & Freddolino, 1986), and the fact that funding sources and third-party reimbursement agencies continue to support a predominately medical model of care. (Merwin & Ochberg, 1983)
- Resistance to supporting less tangible services--Many psychosocial rehabilitation services such as case management; outreach; and supportive living, working, and learning are largely invisible to all but the few who are directly affected by them. On the other hand, hospitals, nursing homes, group homes, homeless shelters, and other facilities are tangible, visible manifestations of the expenditure of tax dollars. Consequently, many funding authorities prefer to fund the latter, less effective but more palpable, facilities. (Merwin & Ochberg, 1983; Tischler, 1987)

Implications for policy/program, training, research, legislation, and service delivery changes

I believe there are four basic strategies to address the obstacles enumerated about that the field should consider as we move into the 1990s: 1. establish a nationwide initiative to change prevailing assumptions about people with severe mental disorders; 2. modify existing programs to enhance their effectiveness; 3. generate credible data; and 4. increase the effectiveness of groups that advocate on behalf of people with severe mental disorders.

1. Change prevailing assumptions

We must launch a potent and convincing national campaign to counter unsubstantiated and injurious assumptions about the abilities and potentials of people with severe mental disorders. This could be accomplished through: a) a major national anti-stigma and public awareness effort, labeled something like "Right to Recovery," and supported through NIMH in collaboration with the major national constituency organizations; b) designating the theme for the next decade of rehabilitation, "Recovery through Rehabilitation;" c) packaging and widely disseminating information briefs based on research and programmatic experience on client's ability to recover; d) state legislation and policies that direct available resources toward programs that help clients recover; and e) a concerted research effort toward identifying the critical ser-

vice elements and environmental factors that lead to positive outcomes and recovery.

I believe the above actions are crucial toward moving forward into the 1990s and advancing the use of rehabilitation to improve the lives of people with severe mental disorders, because it will affect the way clients view themselves, attract increased workers to the field, improve the effectiveness of existing mental health resources, aid community integration and acceptance, and potentially increase the flow of resources allocated to services for the population.

Program experience has shown that positive attitudes of staff can have a profound impact on the way clients view themselves, and increase self-esteem, progress, and growth. (Brooks, 1988; Unger et al., 1987) Much of the success of the 269 clients with severe mental illness who participated in the Vermont Longitudinal Study (Harding et al., 1984) was attributed to the use of an approach grounded in positive expectations (a basic value of the rehabilitation approach(and the goal of restoring 95 percent of the clients to a satisfying life. (Brooks, 1988) Conversely, limited expectations, which generally pervade the more traditional approaches, tend to foster negative behaviors and invite failure. (Anthony, 1984; Zipple et al., 1987)

Changing assumptions will attract workers; most people prefer to work in an atmosphere of hope and progress. For instance, the staff involved in working with clients in the Vermont Longitudinal Study found that their work became fun, exciting, and rewarding, because they were watching "hopeless" people make dramatic progress. (Brooks, 1988)

Changing attitudes about clients would improve the use of existing resources by focusing those resources on programs that help people to recover and, thereby, reducing the extent to which people with mental disorders make future demands on the mental health system. For example, many traditional programs are using resources ineffectively in trying to serve a young adult population that resists traditional services and diagnostic labels. (Zipple et al., 1987) Instead, resources could be used more effectively on apporaches such as the university-based program currently being demonstrated by the Boston University Center for Psychiatric Rehabilitation, which is transforming "treatment-resisent" young adults with histories of homelessness, prolonged social isolation, and long hospitalizations into college students and workers. (Unger et al., 1987)

One of the major obstacles to community acceptance is the occasional unconventional behavior exhibited by some clients. Public education is helpful in increasing understanding of mental disorders, but changing attitudes about the client population could rapidly advance community integration and acceptance. As staff accept and act on the fact that most people with severe mental disorders can change their behaviors, they will be increasingly effective in helping clients gain control over the behaviors that cause the community to reject them.

Lastly, changing assumptions about clients could have a significant impact on people who make decisions about resources. Care for the long-term, mentally disabled population is viewed as a continuing drain on resources that does not reduce the need for future expenditures of the same kind. As legislators come to understand that many people with severe mental disorders can become productive members of society, even contributing to tax revenues, expenditures on mental health and rehabilitation services will increasingly be viewed as "investments," inspiring a powerful new incentive for increased funding support.

2. Modify existing programs to enhance their effectiveness

The second major undertaking involves modifying current programs in order to maximize effective use of limited existing resources. This could be accomplished through: 1) listening to clients and family members and incorporating their input into program design and operation; 2) supporting research to document the impact of client and family involvement on program quality; 3) modifying rehabilitation approach; 4) using less restrictive and generally less costly) alternatives; and 5) improving staff competence through relevant training.

3. Mandate a rehabilitation approach

While we need to learn more about what works best and why, we already know a great deal--particularly about what does not work, and that certain approaches work better than others. We know, for example, that inactivity and lack of involvement cause further and unnecessary deterioration (Mechanic, 1987), while rehabilitation and social supports increase coping ability, decrease symptomatic behavior, and enhance mental status and quality of life. (Anthony & Dion, 1986; Mosher, 1986) Funding authorities should, therefore, require that community programs use a rehabilitation approach.

4. Use less costly natural support alternatives

Rather than relying heavily on the formal system, rehabilitation programs should move forward into the 1990s by taking more advantage of available resources and opportunities in the community that can meet many of the clients' needs. I believe the community support and rehabilitation paradigm for the 1980s was a vast improvement over the segregating and stigmatizing institutional and limiting viewpoints that preceded it. However, much of community support still speaks to concrete places, albeit in the community, but nevertheless separate for living, working, and socializing. As 1988 Switzer Scholar Dr. Agnes Hatfield expressed so well in her paper, many clients prefer rehabilitation in settings outside the formal system such as adult education classes, churches, and recreation centers which exist in most communities. Therefore, I can envision community support and rehabilitation in the 1990s expanding its domain to offer services and supports beyond the walls and formal system boundaries for those clients who prefer this approach. Increasing use of mainstream resources will also help clients integrate more readily into the larger society than would otherwise be possible, and will also reduce the need to use more costly, formal services and supports. (Mosher, 1986)

5. Improve quality of staff

People make programs. Clearly, even if we had sufficient resources to support the kinds of approaches envisioned by Anthony, we will never actually have them until we have the staff to provide them. The mental health system, therefore, must assume greater responsibility for working with univer-

sities to assure adequate pre-service training and education for students and post-service training for clinicians in the skills and knowledge needed to work in a rehabilitation-oriented, community-based service system.

As a first step, legislation and policies must be altered, so that salaries, benefits, and other incentives are increased, in order to attract students to the field and to retain quality staff. The second step is that all staff should be required to become certified rehabilitation workers, that is complete a requisite number of hours of training and demonstrate the knowledge, attitudes, and skills needed to work effectively to help clients to recover. Many programs continue to rely on untrained staff. Because of certain inherent abilities, they may be quite effective, but they will never command the salary and professional status accorded other credentialed staff.

Therefore, to attract and retain quality staff (which will also improve service effectiveness), states must expend resources on training and retraining.

5. Generating credible data

The community support and rehabilitation movement of the 1980s has been characterized by enthusiasm, missionary zeal, and personal commitment which has, in large part, been responsible for much of the substantial progress made during the past decade. However, if we are to move forward and address the obstacles cited above and assure continued progress, I believe we must supplement the powerful emotional appeal of the movement with hard data derived from rigorous research. We need to further test and confirm our assumptions about the cost and effectiveness of rehabilitation vis-a-vis traditional approaches, and we need to identify which lead to outcomes that are important to clients, families, practitioners, and decision-makers. Such information will provide irrefutable evidence to counter narrow views of clients and their service needs, increase program effectiveness, and significantly influence legislative and executive support for rehabilitation programs. Furthermore, unless we do begin to measure the success of our programs rigorously and quantitatively, we will continue to struggle for resources and face the threat of having current programs curtailed or eliminated.

In order to generate needed, credible data, it will be necessary to change policies and influence the research "establishment" to institute a more balanced research agenda. Federal and state mental health research is substantially underfunded overall (Goodrick, 1987b); but the funds that are available are not supporting a balanced research agenda (Anthony, 1984). With the significant advances in the neurosciences, research and the research-funding organizations have focused on studying brain biology and psychopharmacology, rather than emotions and behavior. (Goode, 1988) No one would deny that research on the biological etiology of mental illness is crucial, but no more so than expanding our understanding of effective service approaches. Therefore, research in the 1990s should be expanded to key areas such as outcomes of rehabilitation service approaches including use of natural supports, the net cost of services, self-help approaches, self-management of symptoms and behaviors, client-empowering case management services, and effective rehabilitation services for the increasing numbers of elderly people with severe mental disorders, and young people with mental disorders complicated by substance abuse problems.

6. Increase the effectiveness of groups that advocate on behalf of people with severe mental disorders.

The nation's fiscal retrenchment has created a situation in which the American taxpayer is willing to finance, at most, only the most critically needed services for the most gravely disabled people. (Tischler, 1987) Unfortunately, under these circumstances, few legislators are willing to risk promoting increased resources for additional programs without strong external inducement. I believe that the strongest external inducement comes from the users of the services--the clients and their families. For example, the power of family advocates was recently demonstrated in Virginia where, through the leadership of the family movement, members of a coalition of 10 mental health advocacy groups persuaded Governor Gerald L. Baliles to increase funding for community-based programs by $65 million. (Evans, 1988, page A22)

Therefore, if we are to move forward in the 1990s, reprogram existing resources toward more effective approaches, and obtain additional resources to support increased services, the federal level, states, and communities must make a concerted effort to educate the consumers and provide opportunities for meetings and coalition-building. NIMH has been distributing to families and primary consumers thousands of copies of "Toward a Model Plan for a Comprehensive, Community-Based Mental Health System," developed in response to recent legislation, P.L. 99-660.

This document describes a client-centered, rehabilitation-oriented service system, which is consistent with Dr. Anthony's vision. States should institute policies to assure strong family and client involvement in the planning processes that will be ongoing during the next three years. If the constituents are involved in formulating state and local services plans (and these will be far superior because of their input), they will be strongly motivated to advocate for their implementation.

Conclusion

Dr. Anthony's paper has presented us with a positive, human vision of rehabilitation in the 1990s. Now we must think how we can overcome continuing obstacles and move forward to realize that vision. I believe we must first adopt and assertively promote a positive attitude toward healing clients and eliminate old assumptions that have resulted in ineffective services, inadequate resources, and wasted lives. We must then stop producing staff with outmoded skills and attitudes, and establish an appropriate system of incentives and rewards for properly trained staff. Finally, we must increase effective, rehabilitative services through legislative and policy changes, listening to clients, incorporating the use of natural supports, expanding research on community support and rehabilitation services, and fostering advocacy efforts. Since we are a movement of acronyms (CSP, CSS, CRTs, SSI, NAMI, etc.), I propose we add one more to capture the essence of our renewed vision of rehabilitation for the next decade--the development of truly FINE services, services that are flexible, individualized, normalized, and empowering.

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☐ Professional $20.00 ☐ Student $8.00
☐ Affiliate $20.00

National Rehabilitation Counseling Association
☐ Professional* $30.00 ☐ Student $12.00
☐ Member $30.00 ☐ Affiliate $12.00
☐ Life** $500.00

** Please attach evidence of educational attainment (Transcript or copy of graduate degree)*
***Payment may be made in one $500 sum or in four consecutive yearly payments of $125.*

Vocational Evaluation & Work Adjustment Association
☐ Professional $20.00 ☐ Student $5.00
☐ Associate $20.00

***If applying for membership in more than one division, please indicate the division to receive rebate:** _____

The portion of the membership fee set aside for NRA's two publications is: $5.40 for the **Journal of Rehabilitation** and $3.60 for the **NRA Newsletter.** NRCA sets aside $4.50 for the **Journal of Applied Rehabilitation Counseling** and $2.75 for the **Professional Report.**

Revised: May, 1988

Note: Dues amounts effective through December 31, 1988
Several payment options may be available. Check with your local chapter.

Please make check payable to:
National Rehabilitation Association: Total $_____

Credit Card: ☐ **MasterCard** ☐ **VISA**

Number _____ **Exp. date** _____

Signature _____

National Rehabilitation Association

Founded in 1925, the National Rehabilitation Association is dedicated to improving the quality of life for persons with disabilities in the United States. Membership is comprised of rehabilitation professionals, including administrators, counselors, job placement specialists, secretaries, vocational evaluators, instructors, independent living providers, people with disabilities, family members and other interested citizens. The National Rehabilitation Association is the oldest, largest and strongest advocate for persons with disabilities. We are proud to be called the "Voice of Rehabilitation."

Share Your Voice With Ours
Join NRA Today!

National Rehabilitation Association
633 South Washington Street
Alexandria, VA 22314-4193

Mary E. Switzer Memorial

To perpetuate the memory of a great woman and a great leader in the field of rehabilitation by establishing a memorial that will expand and enrich services to persons with disabilities

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Alexandria, VA 22314-4193